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ABSTRACT

This special issue of a periodical focuses on building support and resources for families of children with special needs. It contains 13 articles in addition to descriptions of 10 programs serving special needs families at the local level, a list of 15 resource organizations and 10 publications/audiovisual aids, and a message from the coalition's president. Titles and authors of the 13 articles are: "Parents Take Priority in Family-Centered Care" (Elizabeth Jeppson); "A Fully Human Life" (Linda Gilkerson); "Supporting and Strengthening Families: New Visions, New Directions" (Carl Dunst); "Family Bonds: The Binding Force" (Patricia McGill Smith); "Parent-to-Parent Support: A Federal Program" (Martha Ziegler); "The Parent/Professional Relationship: Complex Connections, Intricate Bonds" (Madelyn Anne Iris); "Special Needs Children, Special Needs Fathers" (James May); "Respite Care" (Shirley Cohen); "New Perspectives on Financing Health Care" (Julianne Beckett); "A Life Span Perspective" (Ann Turnbull); "States Take Leadership Role in Prevention/Early Intervention Programs for Young Children with Special Needs" (Eleanor Szanton); "For Preschoolers with Handicaps--Free Appropriate Public Education by 1991-92?" (Pascal Trohanis); and "Networking in New York State: A Green Thumb Experience" (Lisa Grippo-Gardner and Catharine McHugh). (JDD)

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Family Resource Coalition
Report

FOCUS: Families of Children with Special Needs

Building Support and Resources for the Family

Volume 7, Number 2 — 1988

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Special Issue

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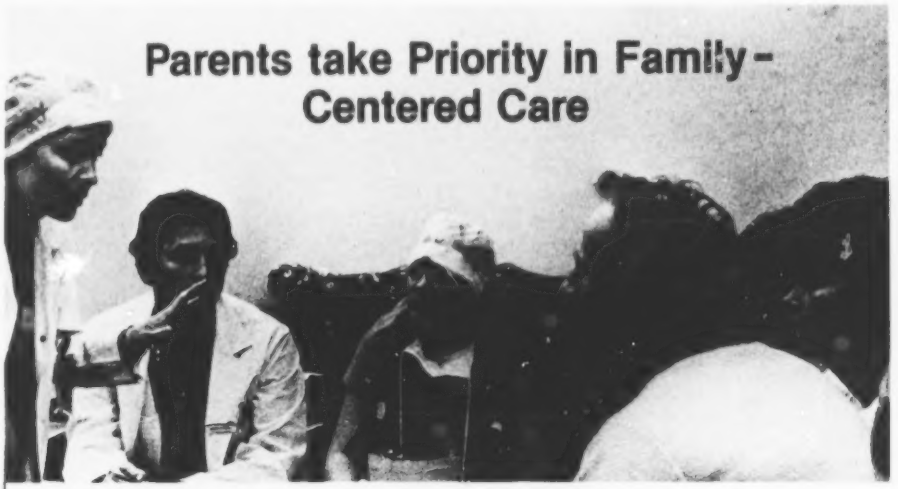

Parents take Priority in Family-Centered Care

by Elizabeth S. Jeppson

Families have the central role in caring for their own members, and the goal of policy should be to enable families to carry out their responsibilities to nurture their children and encourage their most effective development. (Hobbs, Perrin & Ireys, 1983)

Since 1986, the Association for the Care of Children's Health (ACCH), with support from the Office of Maternal and Child Health, has worked with a broad range of parents and professionals across the country to articulate and define the concepts of family-centered care. Our work has been based on the belief that families have the pivotal role in the lives of their children, and that professionals should strive to support families in their natural caregiving roles by building on their unique strengths as individuals and as families.

Although the context of our discussions about family-centered care has been the health care system, it is our belief that the principles of family-centered care apply to all settings — education, early intervention, mental health, and social service as well as child health care — anywhere that parents and professionals work together on behalf of children and families.

Following are the eight major components that have been identified as the key elements of a family-centered approach to care. Although each element is presented and discussed separately, it is equally important to consider them as a whole. Together, they constitute a new philosophy of care that challenges many of our entrenched attitudes and calls for new approaches in clinical practice.

As you read the elements, think about your own setting or practice. Are there ways in which your approach to families could become more family-centered? What barriers, either personal or organizational, can you identify to implementing a family-centered approach to care? What benefits can you see for yourself and for the families you work with in practicing this new philosophy of care?

The Elements of Family-Centered Care

■ Recognition that the family is the constant in the child's life while service systems and personnel within those systems fluctuate.

This is the most crucial component of family-centered care. Because the ultimate responsibility for managing a child's health, developmental, social, and emotional needs lies with the family, systems of care must enable families to function as primary decision-makers, caregivers, teachers, and advocates for their children. *Continued on p.2*

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Families are the durable thread in the life of a handicapped child. Public agencies and private agencies are transitory, dropping in and out based upon the condition, the complication, or the chronological age of the child. (Freedman, 1986)

Recognizing and respecting the pivotal role that families play in the lives of their children means that professionals must learn to value the parents' judgment, to respect their priorities for their own children, and most importantly to ensure their efforts are designed *to support, not supplant* the family in its caregiving role.

■Facilitation of parent/professional collaboration at all levels of health care:
- **care of an individual child**
- **program development, implementation and evaluation**
- **policy formation**

The formation of a true and equal partnership between parents and professionals at all levels of care is the driving force in family-centered care. Developing these relationships, however, often requires new skills.

For a number of years, the attitudes of professionals working with families have seemed to say, "Tell us what your problem is, and we'll fix it." The professionals were, in a sense, in control. We professionals need to change our orientation. We need to reframe that question to ask simply, "How can we help you?" We need to begin to view our work with families as a partnership in which we are the consultants but the families are in charge, and it is on the care of their child that we are in fact consulting them." (Barnard, 1985)

In order to be more effective consultants to families, professionals must develop more opportunities, both formal and informal, to learn about the perspectives of families and to work together with parents as equals at all levels of care.

■Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate and supportive manner.

The sharing of information between parents and professionals is an integral part of family-centered care and the cornerstone of parent/professional collaboration. In order to participate fully in the decision-making process, parents must have complete and ready access to information—not only information specific to the child's special needs, but also information about community resources, support groups, and the pros and cons of treatment choices. Professionals must become sensitive to the ways in which information is presented, and ensure that the type and amount of information conveyed truly reflects the family's concerns.

■Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to families.

The support needs of families are diverse and varied and change over time. Translating family-centered care into practice means developing programs and services that address the full range of these needs, that support existing family strengths and balance the demands of care. Too often, the development of comprehensive programs and community support services have not kept pace with advances in medical technology or with the shift from institution and hospital care to home and community care. Among the vital support services that must be available to families caring for children with special needs are in-home health care services, care management services, respite care, parent-to-parent support, family resource libraries or parent information centers, equipment loan or exchange programs, and transportation assistance.

■Recognition of family strengths and individuality and respect for different methods of coping.

Family-centered care reflects a balanced view of the child and family, and considers the family's strengths and resources as well as needs.

This approach also requires that professionals develop sensitivity in relating to families whose values, customs, and lifestyles may be different from their own. As one mother states, "I have to provide for my children in the context of my family, and my values, and my ideals, and my lifestyle." (Kramer, 1987) In practicing family-centered care, professionals must accept and support each family's individuality.

■Understanding and incorporating the developmental needs of infants, children, and adolescents and their families into health care delivery systems.

Family-centered care goes beyond the child's identified special needs, to recognize and promote healthy family functioning and to encourage the child and family to fulfill "normal" developmental needs.

Regardless of handicapping conditions, our children have the same needs as able-bodied children. Handicaps... do not cripple their innate desire to grow, to develop, to be accepted, to belong, to be loved and to love. Their need to feel whole is no less than that of children without handicaps. (Downey, 1986)

Encouraging the family to meet and support all aspects of the child's development is an important part of family-centered care.

■Encouragement and facilitation of parent-to-parent support.

What parents offer other parents, through literature, friendship, and organized peer support, is respect — with empathy — and without the burden of clinical assessment — a precious resource for families in crisis. (Oster, 1985)

Parents are a tremendous support to other parents and to professionals. They are a resource that we have vastly underused. Sometimes professionals who offer support to families may feel in competition with parent support groups. Parent-to-parent support should be seen as complementing rather than competing with the type of support and services offered by professionals.

■Assurance that the design of health care delivery systems is flexible, accessible, and responsive to families.

No one program, service, or approach is appropriate for every family. Family-centered care seeks to provide a range of options to families, seeking their input in the design of programs and allowing them to be decision-makers about when and in what ways they want to receive services. As one health professional has stated, our goal should be "to design our systems of care so that parents can get on and off the train depending on their needs." (Freedman, 1986)

The development of a family-centered approach to care reflects the evolution of our knowledge about children and families. As we have learned to listen openly to families and to form partnerships with parents, the practices we promote and the programs and policies we develop have changed and improved. It is hoped that the above eight principles of family-centered care will be helpful guideposts in our continuing efforts to improve the quality of care for all children and their families.

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A Fully Human Life

by Linda Gilkerson

Recently, I came across a newspaper article about Steven Hawkings, the well-known astrophysicist who has ALS, or Lou Gehrig's disease. He is severely disabled. Physically, that is. He commented that he was lucky to have chosen a career that is primarily mental work, that he had a wonderfully supportive wife and family, and that his colleagues have been unfailingly helpful. "Fortunately," he said, "my disability hasn't been a serious handicap."

My guess is that, at some point in our lives each of us has wondered about what it means to be disabled. Maybe we have a friend who had polio, or a neighbor who has a child with a hearing loss, or a high school classmate who was injured in Vietnam, or a cousin who has cerebral palsy, or an officemate whose new baby was born with spina bifida.

Perhaps we have noticed the feelings that come up for us when we are with someone with a disability—when we walk past a woman putting her wheelchair in the backseat of her car, when we enter an elevator where several deaf adults are involved in a sign-language conversation, when we watch the Special Olympics on TV, or when we check out at the corner market and the owner's son who has Down Syndrome carries out our bags.

Because we live in a society that has rigid standards for appearance and performance and that places a high value on independence, it is hard for us to imagine that the lives of persons with disabilities can be full and satisfying. In fact, in the literature on family adjustment to a child with disabilities, the most common framework for disability is that of a tragic event. Is it possible that there are other ways to think about what a disability means to an individual, to his or her family, and to society at large?

Let's start by considering the difference in meaning between the words disability and handicap. Traditionally, disability refers to actual diagnosed medical condition, while handicap refers to the extent to which it impairs somene's functioning.

The degree to which a disability handicaps an individual depends on many factors. Hill (1949) provides a way to understand a crisis that is very helpful in explaining how the same disability can affect people in such different ways. He calls the model the ABCX Model. In this framework, A is the stressor event, B is the resources that an individual/family have to bring to bear on the crisis, C is the personal meaning that the individual/family gives to the event, and X is the resulting level of crisis. Let's use Steven Hawkings's experience to see how this model applies.

A, the stressor event is ALS disease. Among the resources (B) he has to bring to bear on the situation are strong support from his family and his colleagues, the type of work he does, and his previous accomplishments and stature in the field. The personal meaning he gives the event (C) is, to paraphrase his wife, "Steven doesn't give in to his disability and we don't give in to him." In other words, his interpretation of his condition is that it is one that can be handled. The resulting level of crisis (X) for this individual with ALS disease is mediated by the considerable resources he has, and by the personal meaning that he attributes to the disease ("I can handle this"). Another individual with the same condition who has fewer resources and/or who views the disability in a different way would have a very different outcome.

It is surprising for us to realize how influential the meaning that an individual gives to their disability is to their ultimate functioning in the world. In fact, the rehabilitation literature suggests that the personal meaning assigned is the most powerful predictor of long-term adjustment to disability, more powerful even than the type of disability one has or the severity of the condition. Thus, how an individual feels about him/herself is one of the most important aspects in his/her adjustment to disability.

In looking at our own beliefs about disability, what has been our contact with persons who have physical or mental differences? What feelings do these experiences evoke in us? Can we learn to separate how we feel about a disability from the individual who has the condition? Are we willing to re-evaluate our views in light of what persons with disabilities have to teach us?

"The deaf are not ready yet to function in the hearing world" are words that forever changed Gallaudet College and caused a whole nation to re-examine its beliefs about persons with hearing impairments. Intuitively, all of us—lay persons and professionals in the field—understood the depth of the students' feelings and the correctness of their position. Perhaps it is the hearing world that has not been ready to live with persons who are different from ourselves. Are we ready to listen?

Adults with disabilities often say it is the attitudinal, rather than the architectural barriers that are the hardest to overcome. Now that P.L. 99-457 greatly expands the possibility of services for young disabled children and their families, it's time to take the next step: to re-examine our views of disability, to tackle the attitudinal barriers, and to develop a framework that empowers families to love their children unconditionally, and enables children to reach their fullest potential.

Children can learn to live with a disability. But they cannot live well without the conviction that their parents find them utterly loveable.... If the parents, knowing about his (the child's) defect love him now, he can believe that others will love him in the future. With this conviction, he can live well today and have faith about the years to come. (Bettelheim, 1972)

What framework would empower children and families to have the conviction Bettelheim speaks of? I posed this question to my friend Marsha Saxton, a counselor of persons with disabilities, an author (1987) about women's issues and disability, and an adult with a physical handicap. She said that such a new view would acknowledge that disability involves a loss of some capacity, that it is usually accompanied by some objective hardships, and that it is an equally valid, fully human lifestyle.

We know that a child's self-esteem develops both from within—the child's own sense of competence—and from without—the approval he receives from others. Because cultural beliefs affect how families feel, and how families feel affects children, we are compelled to look again at society's beliefs about disability—to look again within ourselves.

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Supporting and Strengthening Families: New Visions, New Directions

by Carl J. Dunst

It isn't often that we have a broad-brushed opportunity to rethink and reshape the direction of family support services. Public Law (P.L.) 99-457 provides one such opportunity if we approach implementation with new visions and new directions of what family support can and ought to be.

P.L. 99-457, passed and enacted into law by Congress on October 8, 1986, re-authorized the Education of the Handicapped Act and amended the Act to include an early intervention discretionary program to meet the special needs of handicapped infants and toddlers and their families.

The Act is a watershed piece of legislation in a number of respects, not least of which is the emphasis given to family-focused assessment and intervention. Whether or not policy makers and program builders take full advantage of the Act as a way of supporting and strengthening family functioning (Hobbs, et al., 1984) depends upon how we ultimately decide to interpret and implement this exciting piece of legislation.

Whether or not the early intervention program is indeed a family support initiative or is simply a traditional child-focused effort dressed in parent clothing is a question that must be answered before implementation proceeds any further. To answer this question, I performed a content analysis of the various federal documents that describe the meaning and intent of the Act. I also identified all non-repeated statements pertaining to child or family needs to determine the major focus of the early intervention program. The various needs statements found in these documents could be grouped into three categories. The statements are shown in the Table.

The first set of statements reflects a traditional child-focused perspective of early intervention. The emphasis is on meeting only the child's needs, most often using educational or therapeutic interventions implemented by professionals or paraprofessionals. In its most extreme and narrow-focused form, this approach violates nearly all the principles that underlie family support initiatives (Hobbs, et al., 1984) and effective helping. (Dunst, 1987; Dunst & Trivette, 1988a)

The second set of statements reflects a narrow-focused family involvement perspective of early intervention. The needs of families are taken into consideration, but only those related to enhancing the development of their children. This perspective is typically operationalized as some form of "parent training."

The third set of statements reflects a broad-based, family-focused perspective of early intervention. In this approach, the needs of the children, other family members, and the family unit itself are addressed as part of the intervention efforts, based upon the assumptions and presuppositions that have increasingly been recognized as the essential ingredients of family support programs. (Kagan, Powell, Weissbourd, & Zigler, 1987)

Although it appears that a broad-based, family-focused approach holds the greatest promise for providing new visions and directions for ways to support and strengthen family functioning, I have been perplexed by the many negative reactions to calls for adoption of this particular perspective of early intervention. The arguments against adoption of a broad-based approach have included, "There are not enough resources to provide services to all people in all areas," "Staff don't have the time to address all family needs," "We can't be everything to everybody," and similar comments. I understand why people make these statements, though I generally find their concerns unfounded.

First, the Act does not state that early intervention programs should provide all resources to all people. The law is explicit in stating that early intervention programs should *assist* families to access needed resources. This requires nothing more than increased awareness of the informal and formal resources and supports that are available or can be created to meet family needs.

Second, if one assumes a broad-based, family-focused perspective of early intervention, the operative word *assist* gets translated into practices that enable and empower families to effectively identify their needs and mobilize resources to meet those needs. (Dunst, Trivette, & Deal, 1988) Doing for families, rather than families becoming more capable of doing for themselves, is explicitly avoided because it represents a form of non-contingent helping that creates dependencies (Dunst, 1987) and is ethically indefensible. (Skinner, 1978)

Third, proponents of the narrow-focused family-involvement perspective of early intervention fail to recognize an important determinant of human behavior, namely, those needs and desires people consider important and to which they will devote their time and energy. (Dunst, et al., 1988) If families and individual family members identify needs other than those related to enhancing their children's development as most important and pressing, they will not likely devote time and energy to carrying out child-level interventions. This relationship is so important, and its implications so far-reaching, that it is worth taking time to briefly review the research that bears upon this principle of human behavior.

In several studies conducted in our own program (Dunst, Leet & Trivette, 1988; Dunst, Vance & Cooper, 1986), we have found that the inadequacy of resources unrelated to child development interfered with the time, energy, and personal commitment of parents to follow through with implementation of child-level interventions. Kolobe (1981) as well,

TABLE: Statements Reflecting Different Perspectives and Orientations of the Early Intervention Discretionary Program

Narrow-Focused Traditional Child-Focused Perspective	Family Involvement Perspective	Broad-Based Family-Focused Perspective
Early intervention services are designed to meet a handicapped infant's or toddler's developmental needs. (HR 99-860, p. 7; EHA, Sec. 672 [2] [C])	Enhance the capacity of families to meet the special needs of their infants and toddlers with handicaps. (EHA, Sec. 671 [a] [4])	Provide early intervention services necessary to meet the special needs of handicapped infants and toddlers and their families. (HR 99-860, p. 6)
Part H . . . focuses exclusively on meeting the needs of infants and toddlers with handicaps. (34 CFR Part 303 #1)	A statement of the family's strengths and needs relating to enhancing the development of the family's handicapped infant or toddler. (EHA, Sec. 677 [d] [2])	Each handicapped infant or toddler and the infant or toddler's family shall receive a multidisciplinary assessment of unique needs and the identification of services appropriate to meet such needs. (EHA, Sec. 677 [a] [1])
Case management includes . . . coordination of early intervention services with other services . . . that the infant or toddler needs. (HR 99-860, p. 8)	A timely, comprehensive, multidisciplinary evaluation of the functioning of each handicapped infant and toddler . . . and the needs of the families to appropriately assist in the development of the handicapped infant or toddler. (EHA, Sec. 676 [6] [3])	The Individualized Family-Support Plan (IFSP) shall be evaluated . . . and the family . . . provided a review . . . at 6 month intervals (or more often where appropriate based on infant and toddler and family needs). (EHA, Sec. 677 [b])
		A statement of the specific early intervention services necessary to meet the unique needs of the infant or toddler and the family. (EHA, Sec. 677 [d] [4])
		Case management services include . . . coordinating and monitoring the delivery of services . . . that the child or family needs. (34 CFR Part 3.3.6)

SOURCES: Public Law 99-457 (Education of the Handicapped Act [EHA] Amendments of 1986; House of Representatives Report [HR] 99-860; Early Intervention Program Proposed Rulemaking, *Federal Register* [CRF], February 18, 1987, pp. 44352-44362

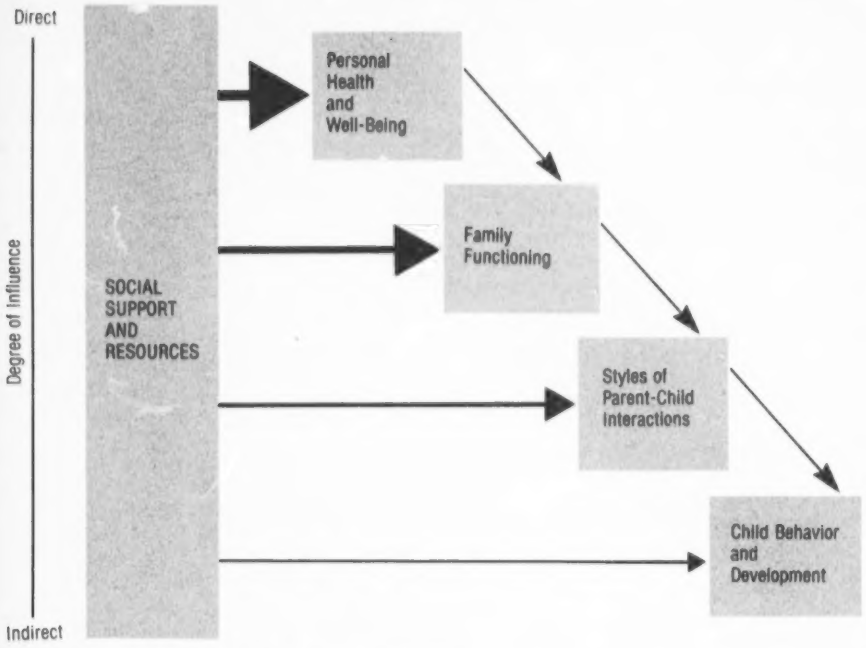

FIGURE. A Model for Representing the Direct and Indirect Influences of Social Support and Resources on Parent, Family and Child Functioning

found that parent adherence to implementation of child-level physical therapy prescriptions was related to the parents' personal assessment of the importance and value of the therapeutic regimens.

In one of the most instructive studies examining the relationship between needs and intervention efficacy, Glenn Affleck (personal communication) found that the positive influences of interventions with families of neonatal intensive care unit graduates were greatest when interventions matched family-identified needs. In contrast, interventions unrelated to family-identified needs had no effects and in some cases negative impacts. Collectively, the results of these studies indicate that needs influence behavior and steer it in certain directions, and that interventions will have the greatest impact if they are responsive to what is most important to a family at any particular point in time. Therefore, the failure to address the broader-based needs of families will almost certainly diminish the effects of efforts to support and strengthen family functioning.

The resolution of whether or not to adopt a broad or narrow-focused approach to early intervention can occur from another perspective as well. Carol Trivette and I (e.g., Dunst & Trivette, 1987, 1988b) have developed a model that describes the direct and indirect influences of social support and resources on parent, family, and child functioning. The model, which is designed as an intervention framework, is shown in the figure.

According to this model, social support and resources influence the health and well-being of recipients of aid and assistance, and support in combination with the other behavior categories influence child behavior and development. For example, child care (instrumental support) provided to a parent of a young handicapped child would afford the opportunity to rest and rejuvenate oneself. This would be expected to influence one's physical and emotional health, which in turn would likely influence interactions among family members, including those with the child, and the particular interactive styles used by the parent would be expected to affect child behavior.

In our model, provision of resources and support provide opportunities to get needs met, which in turn set the occasion for positive transactions among people who strengthen family functioning and promote child development. (Dunst, et al., 1988; Hobbs, et al., 1984) This broad-based perspective not only addresses all family needs but, as a result, has the effects central to the more narrow-focus perspective of early intervention.

To what extent the early intervention program under P.L. 99-457 becomes a family support initiative depends upon how we decide to interpret and implement the various provisions of the law. I have argued for a broad-based, family-focused interpretation. It is only this perspective that is likely to provide new visions and new directions consistent with what we know about the determinants and influences of needs, support, and resources, and how the unique relationships among these optimally influence family functioning.

We may never again have the opportunity to so significantly shape the direction of services to families of young handicapped children. We have a human obligation to seriously consider how our decisions about the meaning and intent of P.L. 99-457 influence intervention efforts. The failure to do so will most certainly be a wasted opportunity.

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Family Bonds: The Binding Force

by Patricia McGill Smith

When a child is born with special needs, parents can be faced with tremendous problems. If the disabling condition is diagnosed immediately, the impact is quick, pointed, and profound. On the other hand, some problems can only be identified after months or years, dragging on undefined, keeping parents in limbo with questions and doubts. Whether the diagnosis is immediate or delayed, parents are crowded by emotions of confusion, fear, and heartache.

In my own case, my daughter, Jane, who just celebrated her eighteenth birthday, was a perfectly healthy and beautiful baby at birth. Within her first year of life, however, she developed a number of problems that were hard to define but eventually led to recognition of the fact that she was developmentally delayed. Eighteen years ago, developmental delay did not translate into "This child and her family need help!"

Today, all kinds of supports exist for parents who will reach out for them. These traumatic periods can be very destructive for a family, and the sooner parents can begin to alleviate some of their feelings of anxiety, anger, and guilt, the sooner they will be able to provide their child with love and acceptance. This article focuses on the reactions of parents on learning that their child has a disability, and on ways in which they can face both the disappointment and the challenge.

Denial is one of the most common reactions. Every parent looks forward to having a healthy baby, and discovering this is not the case, can't believe this great disappointment is happening to them and to their family. Denial often turns to anger which can spread to the husband-wife relationship, come between parents and grandparents, or be directed at medical personnel who have worked with them and their child. Sometimes, in the beginning, the anger is so intense it touches everyone involved and colors almost all interactions. At this point, parents also go through an intense period of grieving and loss.

Another common experience for parents is the sense of losing control over their lives. They find themselves becoming fearful, and apprehension for what the future holds can cause parents to lose their perspective completely. For some parents, a lack of information pushes them to imagine the worst possible prospects with a totally bleak attitude. Many parents have told me, however, early warnings that their child would be unable to walk, talk, read, or write were unfounded, and ultimately the child was able to accomplish these things and more.

Parents often feel a great deal of guilt about their child's condition, and concern about whether they caused the problem. These guilt feelings may be manifested as spiritual or religious interpretations of blame and punishment, and can be aggravated by how others respond to the birth of a child with a disability: "You must be very special—God has given you this trial"; "You will not be given any more to bear than you can handle." While these comments are meant to be supportive, they can have the opposite effect and exacerbate the parents' feelings of guilt.

Sometimes parents go through a period of total confusion, compounded by stress, when faced with new terminology and information regarding the disabling condition of their child. Professionals seem to be speaking a foreign language, and parents often feel they are unable to communicate feelings about their child's disability to friends and family. Needing information but being unable to absorb or make sense of it can cause emotional overload.

Another source of difficulty for parents is the feelings of powerlessness they experience. It is so difficult to differentiate between the things they have the power to change and those they cannot. Parents may find it difficult to develop a positive attitude toward the work they must do to overcome their child's problems, and feeling powerless drives many parents to become over-involved, turning them into a SuperMom or SuperDad who is going to "fix what is broken."

The disappointment that a child is not perfect challenges the egos of many parents as well as their value systems. The birth of a child with a disability is a jolt to their expectations, and there has to be a considerable realignment of expectations before they can cope with the child's problems successfully.

I think the greatest difficulty that can occur is rejection of the child. Parents have told me they not only rejected their child, but the whole idea that the child was handicapped. The most serious form of rejection is a "death wish." When a child is in critical condition or severely involved, that "death wish" is not at all uncommon, although it may be hard to admit and understand those feelings at a later point.

The emotional roller coaster I have described happens to a greater or lesser degree for all families when they discover their child has special needs. These feelings can drastically alter the normal routines of family life, and the changes can harm all members of the family—especially the child with the disability. Not all families suffer intense disruption of their lives, but it is fair to say that normally, this type of crisis will cause substantial change that can either strengthen the family's life or undermine it.

Taking constructive action and adapting positive attitudes can help to alleviate some of the stress. I hope parents will feel free to take what they can use from my suggestions, and that the professionals who work with them will gain greater understanding and insight for having shared the reading.

Stabilizing the Family

Parents need to know from the very beginning that they will survive this upheaval, that they can and will "make it" despite doubts about the burden being too heavy. There are programs, schools, and recreational activities, neighbors and advocates, and all manner of people who will enter their lives to help with the problems. Isolation can be dangerous, and it is extremely important for parents to understand they are not alone, to recognize and value the assistance of a whole cadre of people who are ready, willing, and able to help if parents will just make their needs known.

It can be overwhelming to meet the time and energy commitments that a special-needs child requires. Each family member can contribute in some way and should be included in the child's care. The support of relatives outside the immediate circle of family and friends can be a great help if they have an understanding of the child's needs, and a powerful emotional reinforcement to both parents and children.

Husbands and wives need special empathy for each other as they go through troubled times. Many fathers have confided reluctance to express their own concerns or emotional stress for fear of further burdening their mate or appearing weak. Wives often feel guilty for

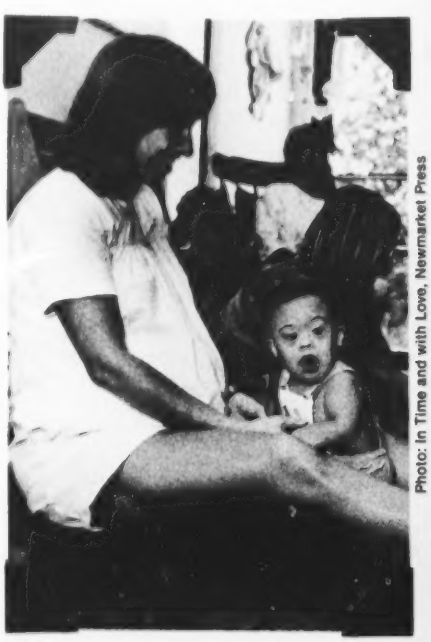

Photo: In Time and with Love, Newmarket Press

Photo: In Time and with Love, Newmarket Press

for the future, learn from the past, but live for the day." The statement taught me that keeping things in perspective helps in dealing with fear, and fear of the future in particular. Getting rid of the "what ifs" and "what thens" can keep the reality of each day manageable.

Parents' well-being is enormously important. They need to learn to be good to themselves, to enjoy life to the fullest, to let laughter release tension and lift spirits; that reaching out for emotional support, being honest about feelings, setting priorities, avoiding self-pity and becoming judgmental, using empathy and understanding to deal with problems, keeping home routines on schedule, recognizing their limitations, and taking time to smell the roses, will all make important differences in how they accept and deal with the challenges of raising a child with special needs.

In conclusion, I would remind parents that one of the most important things to understand is that their child with a disability may be different from other children, but he or she is not less valuable, less important, or less in need of love and parenting. Remember, the child comes first, the disabling condition second.

Sometimes parents will find it hard to believe, but they may come to view their experiences and problems as having strengthened them and their family. We all have choices in the ways we respond to the difficulties we undergo. I have learned many lessons as the parent of a child with a disability, and I recognize that our whole family has emerged stronger and wiser from our trials.

leaning heavily on their husbands. What evolves is a discrepancy, an interruption in the honest feelings which are normally the same for both parties. It can be very strengthening, therefore, for couples to share all their feelings.

Parents need to recognize that they are and will be their child's teacher, advocate, friend, and parent all rolled into one. It is enormously important that parents learn early on that they needn't feel intimidated by the professionals who treat their child. They have the right and obligation to be a part of their child's planning team, and can be involved in every aspect of the decision-making process. Though they may lack information or feel insecure in this role at first, they need to become active, knowledgeable participants. Asking questions can be the first step.

It is also important that as many programs and as much work as possible involving the handicapped child be conducted in the family home or as near to the home as practical. The basic question is, "When each objective is being reviewed, can the activitiy be performed in the home setting?" Planning meetings for the child can be held at home, as well as play therapy, occupational and physical therapies, and other developmental activities. The goal is to integrate as many of these activities as possible into the child's normal life cycle.

Some Practical Advice

There are a number of resources in almost every community that can be helpful to parents: members of the clergy, another parent of a child with a handicap or a support group of "helping parents," an advocacy organization, a state or federal program/ agency, etc. Also, finding sources of current and factual information can be valuable in helping to dispel fears and myths about a child's disabling condition or special needs.

A "recipe for living" that has assisted me the most in my life has been to identify feelings that are painful. When they occur, I have made a commitment that says, "I will reach out and contact someone." Call, write, get in the car, but contact a real person who will talk and share the pain. Pain that is divided is not nearly so hard to bear as pain experienced in isolation. Sometimes professional counseling is needed, and parents shouldn't feel reluctant to seek it.

I have learned that bitterness and anger can drain energy and initiative. Letting go of these feelings has a constructive effect and will help parents maintain a positive attitude and outlook.

Staying in touch with reality and living one day at a time can keep parents from taking on more than they can handle. A very wise person once counseled me by saying, "Plan

Photo: Ada S. McKinley Community Services

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Parent-To-Parent Support:

A Federal Program

by Martha Ziegler

The Education of the Handicapped Act of 1983, P.L. 98-199, established a grant program to support organized parent-to-parent information and training activities for parents of children with special needs. As specified in the law, the purposes of these programs is to enable parents "to participate more effectively with professionals in meeting the educational needs of handicapped children." The Parent Training and Information (PTI) Projects conduct workshops, publish newsletters, respond to inquiries by mail and telephone, and offer other parent-to-parent support services.

From self... to disabled child... to spouse and family members... to other families with similarly handicapped children... to the larger society: This evolution, described so eloquently by Perske and Wolfensberger (1973), is familiar to every parent who has ultimately become an advocate on behalf of disabled children and their families.

Leaders of the 50 PTI Centers have personally moved through this evolution. As parents of children with disabilities and as advocates for other parents, they have brought about major changes in the laws governing the education of handicapped children. In addition to guarantees of rights and appropriateness of educational programs, these new mandates also required a new role for parents.

Most parents, accustomed to using bake sales and selling Christmas cards to keep small private programs alive, were unprepared for this new level of responsibility and meaningful participation. More experienced parents began to develop ways of meeting the new needs for information and skills. Parent leaders took yet another step in their own evolution toward the larger community by forming coalitions that represented the whole range of handicapping conditions rather than separating into individual categories or disability groups.

Peggy Pizzo's book, *Parent to Parent* (1983), describes in detail the dynamic operation of peer support for parents with a variety of special problems in rearing children: racial and geographical isolation; dealing with the death of a child; and rearing a child with a handicapping condition. In a foreword to the book, Dr. Benjamin Spock touches the pulse of the parent coalition movement when he makes the following observation:

The parents of children with disabilities realized that as much as anything else they desperately needed the companionship of other parents with similar problems, in order not only to share knowledge of how to help their children but to overcome the painful sense of inferiority and isolation, of "being different." The blessed sense of acceptance they received gave them the optimism and energy necessary to tackle the other problems.

The "optimism and energy" that have blossomed from that "blessed sense of acceptance" have shaped the style of advocacy that characterizes the training and information programs operated by parent coalitions. It is easy to underestimate the power of the energies liberated by the sudden discovery of peer acceptance after the devastating experience of isolation and feeling of differentness.

Expert observers have noted the values for children which accrue from this liberation of their parents. As long ago as 1968—pre-P.L. 94-142 days—then Secretary of HEW William J. Cohen wrote:

The programs of the Department of Health, Education and Welfare are designed to strengthen individual and family life.... The need for involvement by parents and family members is particularly great in public programs which serve children and youth.... I am convinced that many more parents want to become involved, want to have a voice in the programs that affect the lives of their children. And I am convinced that they will have a great deal to contribute once the doors are opened to them.

Photo: Ada S. McKinley

Through the PTI Centers, parents have an open forum in which they can freely discuss their fears and uncertainties among nonthreatening, accepting peers. For example, as imperative as mainstreaming is, it is not always accomplished without cost. As a handicapped child is integrated into regular school programs, not only does the child sacrifice the warm protection of a handicapped peer group, but parents also lose a readily available peer group that shares similar needs and experiences.

The training workshops and other activities conducted by local PTI programs are helping to provide support services to individual parents that may be as important as information and opportunities for skill development. Leaders of parent coalitions work to meet a variety of changing needs: peer support, knowledge of the law, communication and negotiation skills, forming effective parent/professional partnerships, for instance.

The framers of P.L. 94-142 were careful to include language in the statute itself ensuring parent participation in several key roles. The law provides an individual parental role in planning and monitoring each child's educational program; it also provides for parent participation in each state's planning and implementation of special education policy. To perform these roles mandated by law, parents of children with handicapping conditions must acquire highly specialized information and skills. In addition to learning the procedures necessary for protecting the rights of their children, parents also need to develop those skills that foster strong partnerships between themselves and educators, health care professionals, and others concerned with the welfare of children with disabilities.

All of the fifty PTI projects work toward changing expectations about people with handicapping conditions. From the mild and temporary to the most severe and multiple disabilities, these groups promote a shift in emphasis from the weaknesses and limitations of people with disabilities to their abilities and potential contributions as citizens and taxpayers. Activities encourage change toward these more positive expectations for parents themselves as well as among teachers, principals, and other professionals.

From the point of view of the individual growing child with special needs, application of this theme means designing and delivering educational programs that will prepare that child to live an adult life characterized by independence, productivity, and integration into the community.

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For information about the nearest PTI Center, call or write the TAPP (Technical Assistance for Parent Programs) Project, 312 Stuart St., Boston, MA 02116, 617/482-2915.

The Parent / Professional Relationship: Complex Connections, Intricate Bonds

Photo: In Time and with Love, Newmarket Press

by Madelyn Anne Iris

Ten years ago, when my oldest son was born, I never thought I might one day describe myself as the parent of a child with special needs. Now I have two children with disabilities and my life is far different from the one I had envisioned. For me, being the parent of children with special needs has been a process of becoming. As part of this process I have struggled to develop my own equilibrium, balancing my needs against those of my children and separating my sense of who I am from the fact of my children's disabilities.

My first son, Ari, has a mild learning disability and a sensory integration dysfunction. These disabilities are not serious enough to label him as a "special needs" child, but the tensions created within him radiate outward to affect all his relationships.

While it took me a long time to realize Ari's particular needs, it wasn't hard to see that David, born four years later, was not the perfectly normal baby I wished him to be. Within a week of his birth we learned he had a variety of eye muscle disorders. Although no one mentioned the possibility of underlying congenital abnormalities, it was soon clear that David was not progressing at a normal rate. Even though a diagnosis of severe central hypotonia wasn't reached for more than a year, we already knew David was indeed a child with special needs.

A very important aspect of my becoming the parent of two children with special needs has been the energy I expend on relationships with all the people who come into my life because of the children's disabilities. I call these people "the professionals." Their specialties include medicine, clinical treatment, therapeutic services, social work, and education. Professionals come with their own treatment priorities and personal styles, and it is my task to negotiate a viable relationship with each one of them.

Working with professionals isn't always easy. Although outright conflicts or clashes have been rare, there are many times when I feel we are moving in different directions, and that our goals address very different aspects of the child's life. For example, I find that many professionals view the child as if he were an isolated being, ignoring his place in the life of the family. Yet all my personal and professional experience tells me that families function as units. When one member is removed from the mainstream of family life and treated as though his needs are somehow separate from and unrelated to those of the rest of the family, the family system risks a breakdown. As a parent, I must assure that each member of the family receives the attention he or she requires, and that no one set of needs overwhelms the needs or rights of others.

This might mean neglecting a child's special needs for a short while. Deciding how and when to do this requires continual re-evaluation of my own and my family's values and lifestyle. This is a very personal task, but it can be shared. Guidance from professionals helps me assess my goals and expectations for my family without undermining the integrity of the family system.

Few professionals seem to understand how to work side by side with parents to develop a long-term, comprehensive plan for the child's treatment or care. Instead, they focus their attention exclusively on the single domain of their expertise, ignoring other aspects of the child's needs such as his personal growth and his psycho-social development. As the mother, I see the totality of the child. I look at my children for their present needs but I must also concern myself with their future, well into adulthood. My goals include helping my children function just a little bit better tomorrow, but always with an eye to what this improvement might mean for their lives in general.

Although the professionals I have met are always well-trained in how to greet parents, how to ask questions and conduct an interview, they rarely are comfortable relating to parents as real people with lives of their own. It both amuses and annoys me when I read reports or medical charts and see myself referred to as "the mother" or "mother." This depersonalization creates a barrier to real communication and sharing. I like to think I convey a sense of personal style in all my interactions, and I believe professionals must interpret this style and respond to it just as they would with persons they meet outside the clinical or treatment setting. Seeing beyond the label of "parent of a child with special needs" and recognizing my right to act in an individual and autonomous fashion is an essential factor in establishing a relationship based on mutual respect and equality.

Equally important is the knowledge that my children, regardless of their disabilities, are individuals unto themselves. Too often the child's unique psychological and emotional character is ignored. Professionals must fit themselves to the character of each child just as they fit their treatment to his special needs. To do less is to suggest that the child is only an object to be manipulated, handled, and examined.

I find the parent/professional relationship fraught with risk, and especially challenging in my struggle to maintain a sense of balance. No matter how successful I believe my children to be, or how normal they appear, the services and treatment provided by professionals serve as a visible manifestation of my children's special needs. The very presence of the professional emphasizes our vulnerability.

Also, it is easy to become overly dependent on professionals. They have specialized knowledge I need to properly care for and nurture my children, and at times seem much more capable of understanding and interacting with my children than I do. It is also all too easy to transfer my frustrations, anger, and fears about my child's condition or disability onto the parent/professional relationship. Then, if my child fails to progress, I can explain this as a failure of the professional and thus avoid the reality of the child's condition. While such negative feelings are obviously detrimental to a good working relationship, at times they seem inescapable.

While tinged with intimacy and caring, the parent/professional relationship is also based on a contractual agreement to provide services in a professional and ethical manner. While I always seek those professionals who express a real concern for the child and for the family as a whole, I also look for people who will not fail to provide the promised services. This position may seem contradictory, or at least at odds with all that I have expressed, but the fact merely highlights the confusion and difficulties I face in building relationships with professionals.

Finally, the parent/professional relationship really needs to be viewed as a unique type of bond. When I engage a professional to work with one of my children, whether it be a physician, educator, or therapist, I am offering that professional a special gift—the opportunity to share in the life of my child and my family.

Understanding the complex connections and the intricate bonds that link families and professionals together should be an important goal for all those who serve families of children with special needs. My most successful relationships have been with professionals who are not afraid to work closely with my children and me, and thus are able to respond to our unique set of needs and individual lifestyle, incorporating our family's choices into their own goals for children.

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Special Needs Children, Special Needs Fathers

by James May

"I thought about Noah and how we would never get over him. He's an affliction here to stay, one that continually unfolds."

Josh Greenfield, in his painfully knowing story, *A Child Called Noah,* reveals the terrible ambivalence he feels as a father regarding his autistic son. This "affliction" is the greatest love of his life and also his fiercest enemy. Coming to terms with those bittersweet feelings is Josh Greenfield's greatest challenge. As a man, his cherished ideals for a son have been irreparably shattered. He must now reconcile conflicting conceptions of his role as a father and find new values and expectations that incorporate and encourage his child's full growth and development. In sum, he must redefine himself as a father!

What is that experience like for a man? Why is that so demanding and difficult? What are the feelings associated with such a radical change? We must begin by examining the ways men relate to their children, how these patterns have changed in the past few years, and what these changes mean for a family struggling to cope with the stresses and joys of raising a child with special needs.

The special bond between father and child produces measurable positive effects upon children in regard to their self-esteem, sexual identity, cognitive growth, curiosity, and social skills. (Pruett, 1987) Men are increasingly discovering the many joys of active involvement in their children's lives, and current literature illuminates dads as superb caretakers full of warmth, support, sensitivity, and love.

This involvement can be sorely tested, however, when a child has a disability or chronic illness. The dreams men bring to a child's life—lineage, ego fulfillment, athletic and vocational achievement—are threatened. Some men, unable to come to terms with the perceived loss physically leave the family. Some research indicates that the father, present in the immediate family or not, sets the tone for the acceptance of the child and the attitude each parent and the extended family brings to the child's life. (Price-Bonham and Addison, 1978) Thus, acceptance of his child and the roles he can play in the child's life are of utmost importance. Father's denial limits the infant's and family's emotional and physical well-being.

A man's ability to be an active part of his child's life depends upon previous role conditioning. Men traditionally have been providers, problem-solvers, protectors, competitors, and controllers. They glory in being self-sufficient, in charge, and strong. A special needs child, however, can render a man depressed, weak, guilty, powerless—and very angry. A father's self-esteem is often lowered, particularly if the child is his firstborn, a namesake, and male. (Cummings, 1976) "That I can't control the disability still leaves me confused... that I can't seem to do anything just drives me crazy," bewailed one father at a men's support group.

Realistic expectations for the child must be developed. This child is not the child dad hoped for; consequently, he must also work through his own grief issues, particularly denial, anger, and depression. It is crucial that he accept the child's diagnosis as early as possible, so the child may benefit from remedial therapy and early intervention. (Meyer, Vadasy, Fewell, and Schell, 1985) Too often such services have been offered during a father's working hours. Mothers, therefore, become the resident "expert" about the child's needs, learning style, and habits.

Photo: Peggy Zarnek, National Lekotek Center

Fathers of special needs children perceive few support systems in their environment and commonly report feelings of isolation and loneliness. Parent support programs, while inviting involvement of couples, are generally held during the day and heavily dominated by women. The few men who do attend frequently feel uncomfortable and out of place.

The workplace offers little encouragement; many men find it awkward to share personal concerns with their peers, and a special needs child just cannot "compete" with success stories told around the lunch table. I think of the two men who discovered they were both parents of special needs children, but only after five years of working side by side!

For a man to embrace his child's personal betterment, he must be given a chance to explore his own feelings in a supportive environment. "It's not as if we don't feel things, it's a matter of not knowing what we are feeling," commented a dad during a support program. Men have been taught well: feelings are to be hidden. Painful emotions may be camouflaged by addictive behavior (e.g., overwork or abuse of alcohol) and outward denial ("I'm just fine," "The kid is doing great").

Can we encourage men to willingly engage in their children's lives in responsible, caretaking ways? In his book, *The Nurturing Father* (1987), Kyle Pruett states that "One of the most tenacious obstacles to a man's discovery and sponsorship of his own nurturing capacities is the early and often reinforced lesson that the economic security of his family is his most sacred, possibly only, legitimate domain." The effect of adhering to "culturally defined ideas of manliness" removes a man from his innate capacity to bond and nurture his child.

To counteract such fiction, increased attention on the part of professionals should be focused on programs to benefit the needs of men. Early intervention centers, schools, and hospitals must all direct additional energy toward involving fathers with their children. Some excellent examples exist: Sponsor a "Pops 'n Tots" night, a special classroom where dads participate in activities with their children; if appropriate, take children to father's work environment and let them experience firsthand what dad does everyday; invite dads into the therapy, classroom, and day care centers; develop flexible scheduling that encourages men to attend an Individualized Education Plan; when calling home to talk with mom, also ask for dad; continue to seek increased numbers of men in the field of special education.

Programs of particular value are those that encourage men to be each other's best resources, and recognize the power of men assisting and supporting other men. Fathers' programs facilitate men dealing with their pain as well as sharing the love and joy they have for their special kids. The positive results of father involvement are endless. Family fatigue, stress, isolation, and depression for all family members are lessened. (Markowitz, 1983) Families begin to rebalance themselves in appropriate healthy ways. Our challenge then—as parents and professionals—is to dispute old mythologies and open new doors so that each father may embrace the irreplaceable value he has for his special needs child.

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Respite Care

by Shirley Cohen

Respite care—what does that mean? This is still a common reaction in 1988, more than ten years since respite care programs began appearing around the country. Respite care refers to temporary care given to an individual who has a disability, or who is dependent for other reasons, so that the primary caregiver may experience an interval of relief.

Respite care services are a direct outgrowth of the demands of parents of children with severe disabilities. In the mid-1970s when institutions began closing their doors to children, and some children who had been living in institutions were sent home, parents made it clear to professionals that they needed help in caring for their children. Some parents started respite care programs, and went about raising money to continue to operate them. It was parent voices, too, that sold legislators in many states on the idea of government support of respite care programs.

Why do families need respite care services, and how do they benefit from these services? A parent tells us her story:

"My son Christopher... is labeled 'mentally retarded' and 'autistic'. Chris was extremely hyperactive when he was younger.... At times, because of my son's wild, uncontrolled behavior, I felt I would lose my mind.... Without some relief from him at regular intervals, I simply would not have survived. In fact I think of respite care as a lifeline to sanity...." (California Institute on Human Services 1982, pp. 4-5)

Numerous studies of respite care programs corroborate this concept of service as a lifeline. By giving parents opportunities to rest, recuperate, and spend time with their spouses and other children, respite care improves family functioning, helps normalize families, and reduces the likelihood that families will attempt to obtain out-of-home placements for children under age 18. (Cohen and Warren, 1985)

Models of Respite Care

Respite care may take different forms, with the most basic distinction being whether services are delivered in the family home, in the home of the care provider, or at a service center. Respite care provided in the family home is much like having a babysitter, but one who has knowledge and skills relevant to the care of children with disabilities. Home health aides may be called upon to provide in-home services when a child has special health care needs.

Some parents prefer out-of-home services so they can just remain at home to rest, relax, and renew their energies. Respite care delivered in the home of a provider can respond to this need and have additional benefits as well. An on-going relationship may be formed between the two families involved, resulting in a sense of support and security. This model of service may be implemented using paid providers, volunteers, or parent cooperatives.

Other out-of-home models include drop-in centers, weekend and holiday camps, and residential facilities (group homes) established expressly to provide respite care.

Photo: Family Consortium Project

The Current Service Picture

In the 1970s and early '80s, respite care was often thought of and provided as an isolated service. Today, respite care is seen as one component of a comprehensive system of services needed to support families. Every state now has at least the beginnings of such a support program for families of children with disabilities, although only about half of the states have well-developed systems. Some states offer only a limited range of services, and provide them to just a small percentage of the families who need them.

Services frequently included in family support programs are: respite care, case management, parent education and counseling, adaptive aids and equipment, transportation, home modifications, homemaker/home health aide services, and attendant care. These services are often provided at no cost or on a sliding fee scale basis. Fifteen states now offer cash assistance or vouchers in lieu of or in combination with direct services to families of children with severe disabilities.

While some respite care programs are operated by parent cooperatives or through the use of volunteers, most programs recruit and train paid respite care workers. Training programs implemented by agencies that operate respite care programs may range from one day to thirty or more hours plus courses in first aid and CPR. In good respite care programs, formal training is supplemented by detailed information about individual children provided by their parents.

The two major reservations that families using respite care have voiced about this service are its limited availability and the quality or skills of respite care workers. The former problem can only be addressed by an expansion of service availability, with an increase in services particularly to those families whose functioning is seriously threatened by an imbalance between care demands and family resources. The second problem must be addressed by better matching of respite care workers to family styles and needs, and by the use of professionally trained persons as respite care providers for children with complex care needs.

Some families do not use respite care because the service models available to them don't fit their needs. They may want out-of-home services but only in-home care may be offered. They may want more opportunity to participate in the selection of respite care workers for their child than is allowed by the agency providing respite care in their area. Clearly, states must move toward ensuring a broad range of respite care options that encourage families to choose and shape the services they need.

The Federal Role

In the late 1970s, the Administration on Developmental Disabilities served as a catalyst in the area of respite care, funding several "Projects of National Significance" on this subject. However, federal initiatives since that time have been minimal. Title II of The Children's Justice and Assistance Act of 1986 authorized the Department of Health and Human Services to make demonstration grants to states to establish respite care programs for children with disabilities or chronic illness. Congress did appropriate funds for fiscal year 1988, but the Department of Health and Human Services has not made these funds available to the states.

The most valuable role the federal government could play in this arena is to rechannel the Medicaid funds now used to support institutional programs for individuals with severe disabilities into home and community services. Such a rechanneling of federal monies would allow for the allocation of sufficient, diverse respite care services to make a real difference for families in all parts of the United States.

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New Perspectives on Financing Health Care:

by Julianne Beckett

A Brief Overview

If your child is one of the family of seriously ill children who are confronted with major expenses in hospital bills and little knowledge of how these bills will be paid. Their private health insurance may provide only limited coverage; or, if they have no private insurance, they may need to turn to a public payment program. In the latter case, they might not know which program to apply to, or, once having made application, can be overwhelmed by complex program policies that seem to limit the degree of coverage.

The following is a brief discussion of some of the issues related to this all too common dilemma.

■Private Health Insurance Issues

Private health insurance is available to children either through an employer-based group health policy or through self-purchase by the family. Group policies are a less expensive option; unfortunately, however, their costs are on the rise due to copayments and deductibles. Most policies today are written so that 80 percent of the cost is carried by the employer and 20 percent is carried by the employee.

Before buying insurance, parents should ask for specifics about what the plan covers. Are home health care benefits available? Are there restrictions on providers? Does the family have access to an individualized case management system within the insurance program or through an outside entity? Are there prior authorizations needed for certain services?

In most states, a large group policy holder cannot exclude a "condition" from an insurance policy. They can, however, place a time and/or dollar amount to be met before the policy becomes active. Is there major medical coverage and what is the cap or dollar amount insurance will pay? It should be noted that once the cap is reached, the insurance company has no obligation to continue payment. Therefore, it is important to plan for a secondary payor, perhaps by purchasing an extended coverage policy. Catastrophic or chronic illness can use up dollars very quickly, especially if extended long-term care is necessary. For this reason, caution should be exercised in the purchase of such insurance.

"Self-insured" plans have been created by employers to save money. With few exceptions, these plans limit coverage and this often makes them unable to handle long-term, extended care costs.

One provision that Congress has implemented to prevent employees from losing their jobs because of over-utilization of health benefits has been the COBRA law (P.L. 99-472). Companies with more than twenty employees must cover workers under their health insurance policies for at least eighteen months should the employee lose his/her job. Although the premium may be slightly higher under these circumstances, the employee can use this protected time to become re-employed and meet a pre-existing condition clause in another employer's policy.

Health maintenance organizations and prospective payment options are also available to provide health care access at a reduced cost. However, unless provider lists include physicians with the specialty needed by their child, the family may have problems gaining access to those specialists.

■Public Programs Paying for Health Services

Low-income families have become eligible for the government supported Title XIX Medicaid program, established in 1964. In most states eligibility comes through the Aid to Families of Dependent Children qualifications or eligibility to the Supplemental Security Income Program.

In 1982, it was recognized that a significant number of children who were dependent upon high-tech medical care were being forced to live in hospitals because their homes and alternative institutions were not staffed to meet Title XIX requirements. The government came to realize that this unnecessary hospital care was not only inappropriate, but also very expensive. As a result, the Health Care Financing Administration developed several options a state can use to better serve these children at costs equal to or less than that of institutional care.

The first of these was the "medically needy" program. Persons with an income over the eligibility guidelines can use medical costs to reduce their income to a level that would make them eligible for the state's Medicaid package.

The second option, the "2176 Waiver" programs, allowed states to waive the child's deemed income from their parents and thus leave the child with no assets, making him/her eligible for Medicaid. If institutionalized for longer than thirty days, a child is automatically eligible for Medicaid (20 USC 14). However, if a child should return home, a part of his parents' income is "deemed" his, and therefore excludes him from Medicaid. This "deeming" rule is waived under most of the 2176 waiver programs. States can apply to the federal offices for approval of either a "model" waiver program or a "home and community-based" waiver program. Again, the child has to be eligible for Medicaid if institutionalized, and the cost for care at home must be equal to or less than the cost provided him/her in the institution.

Another option is that states may choose to incorporate this population into their Medicaid program through an amendment to their current state Medicaid plan.

In the area of access to health care services, Congress has extended Medicaid benefits to low-income women and women involved in high-risk pregnancy and their offspring. They have also determined that states can pay for case management and payment for health care provision under the states' Medicaid program.

■Other Special State Programs

It is generally agreed that at best these methods of payment for physician and hospital charges are less than satisfactory, and a number of states have implemented special payment programs (e.g., high-risk insurance pools). When a person has been denied health insurance coverage by several companies or the premium is extremely high, states have opted to provide high-risk insurance covered by a tax on insurers or providers. This spreads the risk across the state's population and reduces the use of Medicaid and other welfare programs. Each state insurance commissioner's office can provide further information about whether funds like this exist in your state.

Parents of children with special health care needs should make two local contacts: the Social Security office to check their eligibility for Supplemental Security Income, and the Department of Human Services (Social Services) to investigate what programs are available and whether state supplemental assistance could provide further help. In addition, there are state level programs that also provide services for children with special health care needs.

All families with special needs children need to be apprised of service options. Toward that goal, the National Maternal and Child Health Resource Center is preparing a guide for families in the area of health care financing that parents can obtain in the near future.

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The following material has been excerpted and edited from Education and Training of the Mentally Retarded *(in press).*

A Life Span Perspective

by Ann P. Turnbull

Frequently, I have characterized parenthood of a child with a disability as being a marathon rather than a sprint. The real issue for families in preventing institutionalization, achieving community integration, and meeting the special needs of their disabled youngsters is to remain intact over time, meet the developmental needs of the child over time, and develop the kinds of relationships that remain resilient and vital over time.

Thus, in taking a long-range view of family life, I propose that early intervention practitioners conceptualize comprehensive family-centered support in terms of the kinds of services that will propel the family to finish the marathon. We need to think very carefully about the expectations of the environments in which families will function, identify critical skills for success, support families to develop those skills early, and enable families to be successful at each stage of the life span.

I would like to share a preliminary and tentative list of marathon skill areas that I feel could comprise a comprehensive family support program.

Meet Basic Needs

First and foremost, basic family needs for food, shelter, health, and security must be met before focusing on other important areas of family life. We must recognize this is part of our mission and can be accomplished through a combination of early intervention support and assistance from other agencies in a coordinated and collaborative fashion.

Learn Self-Awareness

Many families have not had an opportunity to reflect on what their needs and strengths are, and may not be able to articulate their values, coping strategies, resources, pressure points, and joys. Families must take time to explore feelings, options, and preferences to learn about themselves.

Identifying needs is the linchpin of the problem-solving process, and families will go through that process time and time again over the years as they and their child change and face new challenges. Learning self-awareness early can be a major catalyst for long-term success with problem-solving.

Love a Child Unconditionally

There is a phenomenon that occurs for some parents during the early intervention years when they fall in love with who their child might become someday, if only they work hard enough to help the child master sufficient objectives to be less disabled and more normal. A challenge for us to consider in conceptualizing family support is how to help parents prevent the heartache and detachment of not being able to love children with a disability unconditionally—for who they are, just as they are.

I believe a major component of unconditional love for all people, including people with disabilities, is for family members to develop a philosophy about the value of people that is not contingent on achievement, normalcy, success, talent, attractiveness, or progress.

Establish Relationships

Relationships are absolutely vital for family members and their children with disabilities to maximize their access to assistance, emotional support, and general well-being. Unfortunately, many families find it easier to remain isolated in order to prevent the risk of embarrassment or rejection. As families and professionals plan for community integration, perhaps the greatest social security we can offer special needs families is helping people in their community to know them, care about them, commit to their welfare, and generally be open to helping them meet their needs and maximize their strengths.

Experience and Benefit from Emotions

I and every parent I have known find having a child with a disability to be an extremely emotional experience. These emotions don't just occur shortly after diagnosis, but exist over the full life span. Concepts such as chronic sorrow suggest that some of the feelings of sadness and disappointment remain episodic over time.

Families of children with disabilities often find themselves isolated because few other people are prepared to share their emotions. Families desperately need to have their emotions listened to and validated, and they need to know how to channel their emotional energy into constructive outcomes.

One of the big gaps in support services is helping families learn to experience and benefit from emotions. Professionals must learn the humanness of emotion related to disability themselves before they are able to support families to do the same.

Take Charge

Taking charge of a child's education and development involves skills such as problem-solving, collaboration, home-teaching, and community organization. These skills also include the ability to commit to goals based on one's values, as well as the tenacity to overcome problems. I think the capacity for sustained effort is one of the key marathon skills.

Taking charge of one's life is also taking charge of attitudes or perspectives about one's life circumstances. Reframing the situation to focus on positive benefits includes learning to compare oneself to others and to be thankful for one's own condition, finding humor in situations, thinking how things could be worse, and identifying the contributions a child with disabilities can make to family life.

Anticipate the Future and Learn Transitional Planning

Some model programs are assisting families in making the transition from the neonatal intensive care unit to home, from early intervention to preschool, from preschool to kindergarten, etc. Future planning for transition, I believe, involves about three-quarters generic skills and one-quarter specific skills at a given transitonal period. My hope for family support in early intervention is to teach families the generic future planning skills they can apply at *every* life span transition, and then the particular skills they'll need within the next couple of years.

Establish Balance

Families need continual encouragement to think broadly about the priority needs of each family member, and to learn skills for juggling time and attention in order to establish equity within the family. While the education of a child with a disability is a critical concern, so, too, are meeting the economic needs, socialization, spiritual, general housekeeping, and countless other responsibilities of families. Encouraging balance can also lead to the recognition of need for child care helpers and respite care services; time away involving breaks in responsibility can be essential in finishing the marathon.

The skills I have suggested are illustrative, not definitive. They represent, however, a springboard for considering how early intervention can be a launching pad to marathon family living.

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★ States Take Leadership Role in Prevention/Early Intervention Programs for Young Children with Special Needs

by Eleanor S. Szanton

Roughly 1 to 2 percent of all children born in the United States are born with discernible handicapping conditions. About 7 percent are born low birthweight (most of these babies are premature, though some are "small for dates"). Many more children come into the world with disabilities that are not identified at birth or even soon after, but will affect their ability to perform in school. And perhaps most frustrating to families and professionals alike is the fact that another large fraction of children are born with a slight dysfunction which could easily be overcome if identified early and the family had advice and support in addressing the problem. Even though we cannot put percentages on these two latter groups, we know they exist in the population because of clinical experiences and because a much larger percentage of children need special education by the time of school entry (11-12 percent).

What has happened by and large to these children, many of whom have never even been "picked up on our radar screens" during those first six, very important years? What kinds of services have they received or failed to receive, which might have helped them overcome part of their problems before they became more severe? What kinds of supports and services have their families received, or failed to receive, which might improve their ability to cope with the situation? These are some of the questions that a number of states and the federal government began to ask over the last decade.

For well over fifty years, the federal government has taken an interest in helping states improve their services to families with special needs. The Children's Bureau, founded in 1912, was one of the first. The landmark legislation under Title V of the Social Security Act of 1936, creating the Bureau of Maternal and Child Health and Crippled Children, was another. The Developmental Disabilities legislation under the Kennedy Administration, which created major university-based research, diagnostic, and treatment centers for children with mental retardation and other special needs, was a significant expansion of federal funds in this direction.

In the mid-1960s, the creation of Medicaid and its screening tool—the Early and Periodic Screening, Diagnosis and Treatment program—represented efforts to find and treat children who might not come to the attention of private physicians for lack of money. (A very exciting recent set of amendments to this act will now allow states to pay for medical and diagnostic services for small children under the federal poverty level even if they are not on welfare.)

The Headstart program set aside places specifically for children with handicapping conditions. The Handicapped Children's Early Education Program, established in 1968, recognized the need for intervention early. That program has, over the years, funded a number of programs that supplied state-of-the-art models for activity in early intervention.

The Education for All Handicapped Children Act (P.L. 94-142) enacted in the mid-1970s, signalled a new day for families of children with special needs. It required these children to receive a free and appropriate education with educational plans developed jointly and regularly, reviewed by parents and school staff together, and with legally binding procedural safeguards. Amendments of this act began to give states strong incentives for serving children younger than school age.

Now the federal government has begun to extend the provisions of P.L. 94-142 to even younger children. In 1986, the Congress passed the landmark legislation, Public Law 99-457, amendments to the original law. This set of amendments mandates services to children with special needs who are three years of age or older. Beyond this, it provides states with financial incentives to plan for services to children from birth to age three who have already identified handicapping conditions or other conditions that put them at risk of developmental delay.

In itself, this would have been a great achievement. Even more, however, the law requires participating states to plan and develop services based on the understanding that infants and toddlers need services broader than "education," and that their families have an integral role in their progress.

Innovations such as state options as to which will be the lead agency for the Part H (birth through 2) section of the law; establishing an Interagency Coordinating Council representing other agencies working in the prevention area to advise the lead agency; requiring that services for these children include services for their families; emphasizing a single case manager to help families link with a variety of services; and above all, determining that states could opt to cover children who were only deemed to be *at risk* of developmental delay, including those at risk solely for environmental reasons, all make the law a great opportunity for those hoping to address the needs of families as they first become evident.

Opportunities for the Family Resource Movement

Members and friends of the Family Resource Coalition have two clear roles in relation to this exciting development. The first is in spreading the family resource philosophy. Obviously, there are many overlaps of viewpoint between the family resource movement and the framers and implementers of P.L. 99-457. They both place a heavy emphasis on prevention of problems before they become overwhelming to child, family, and service system. Furthermore, they emphasize the family as the true center of activity, even if the child is the one showing most severe problems. Helping the family help the child is a proposition very well known to both groups. In fact, as some of the other articles in this issue suggest, parents of children with handicapping conditions may have a few things to teach the family support movement about the tremendous resource that families can be to those who design and administer service programs.

Photo: Peggy Zarnek, National Lekotek Center

The other role of the family resource movement in relation to P.L. 99-457 is for individual programs to get involved in their own state planning. What process will the state use in deciding who is eligible for service under the new law? Will it include children at risk? If so, will that include children at environmental risk of developmental delay (perhaps including children who have been victims of abuse)? The federal government will soon be issuing regulations about the implementation of P.L. 99-457. If you are a provider, you should know that your state is required to hold hearings on implementation of the new regulations. Is that an opportunity for professionals and parents from your program to become familiar with those who will make decisions in this area, and/or testify about the need to design a system that links and includes services represented by your program?

If the state initiates an aggressive "child find" program, which it is required by law to do, how will that requirement be translated into screening for developmental delay and disability? Might your program have a regular arrangement whereby all your children receive simple screening and evaluation? There is a lot of talk about "mainstreaming" children with handicapping conditions into ordinary day care or preschool programs. Of course, families with special needs children need to talk to each other, as some of the other articles in this issue show. Some, however, are ready and anxious to be "mainstreamed" into more general family support groups. For example, it is very comforting for the parents of a special needs child to realize that their child's particular behavioral crisis is actually experienced by many parents of two-year-olds.

In summary, the advent of P.L. 99-457 presents advocates for families and children with an array of exciting opportunities. States are beginning to make linkages between more general prevention and more specific early intervention services. It is essential that those who run and those who promote family resource programs become part of this process for the good of the families and small children within their state and community.

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★ Texas Early Childhood Intervention

In 1981, the state of Texas authorized the initiation of a program which would use state funds to develop comprehensive service programs for children—prior to school age—who were handicapped or at risk of disability. The state appropriated approximately $6 million per year for this endeavor. It set up a highly unusual interagency government entity, the Early Childhood Intervention (ECI), to set policy and oversee the administration of the program. This unit is made up of a high level representative from each of the Departments of Health, Education, Human Services, Mental Health, and Mental Retardation, as well as a parent appointed by the Governor's office.

ECI now has 71 programs. Its annual budget is $10 million, to which $5.5 million can be added from old and new federal funds. Each program has a combination of developmental intervention, physical and/or occupational therapies, a strong family component (offering training, counseling, support groups, usually a choice of home-based or center-based activities, as well as group or individual activities), and case management with strong linkages to other social services. Programs exist in both private and public agencies, school districts, universities and colleges, even in the neonatal intensive care units of local hospitals.

The programs serve any child 0-5 who is at established risk or suspected at risk of developmental delay. The state is committed to serving up to approximately 18 percent of all young children and their families as funds permit, under present definitions of "at risk" (it expects to serve 3 percent under P.L. 99-457). The state will reimburse for family-focused services. This year the annual ECI conference will be on FAMILIES, and is being organized by the newly hired parent of a handicapped child on the state staff.

ECI is also embarking on a pilot High Priority Infant Tracking Program, to be instituted in 30 counties by 1991, to check the status of all babies born in the county. Counties must have an interagency follow-up effort in place, with interagency councils and a strong public health component, using a giant recall system to track families for check-ups.

Texas views the funds from P.L. 99-457 as well as the requirements for an individualized family service plan as a fine opportunity to increase the scope of its work and to serve many more children than just those with handicaps discernible at birth.

For further information, contact: Donna Samuelson, Early Childhood Intervention, 1100 W. 49th St., Austin, TX 78756, 512/465-2671.

★ Connecticut's Recent Activities

The State of Connecticut has also appropriated some of its own money for early prevention and intervention programs which tie in with P.L. 99-457. In 1987, the state legislature allocated close to $300,000 to erect a comprehensive system for locating, screening, instituting further diagnostic work, and then serving all children under three years of age who are suspected of being at developmental risk in the north central region of the state. The "Demonstration" area includes Hartford and comprises one-third of the state population. When federal funds for P.L. 99-457 became available, state administrators decided to devote much of them to the same area in order to show how such a comprehensive system, adequately funded, could work. Next year, therefore, the demo will have more than half a million dollars for this purpose.

The executive branch of the state government has shown as strong a commitment to this effort as has the legislature. One illustration of this fact is that very high level state bureaucrats attend the interagency coordinating meetings. Commissioners of the Departments of Health Services, Human Resources, Income Maintenance, Mental Retardation, Education, and Children and Youth Services, among others, meet monthly to try to create a seamless web of services. Their lower level representatives meet more frequently as an interagency working group, which is also the steering committee for the demo project.

Since P.L. 99-457 will become a mandate to serve children under age 6 in the state of Connecticut, the Commissioners are concerned about the number of children they will be held legally responsible for serving. At the same time, the state's Department of Children and Youth Services is considering ways to expand its prevention and family support activities, using a case management model. The opportunities for tying federal, state, and private demonstration monies together for prevention and early intervention are obvious.

The demo project is presently gearing up to receive any family that has requested help or has been referred by a professional. Such a referral could come from a family resource program concerned about the developmental progress of a particular child. (Consultation with the family and parental consent would be necessary at every step.) After screening and assessment, an initial individualized family service plan will be developed. Each child and family served will be assigned a case manager or family advocate who will help them choose from an array of free services. Here again, these services might well include a family support or family resource program.

For more information on this state system, contact Virginia Volk, Unit Coordinator, Early Childhood Program, State of Connecticut, P.O. Box 2219, Hartford, CT 06145, 203/566-6584. Those who wish more information on the demonstration program should contact Susan Epperson Vater, Birth to Three Interagency Service Coordination Center, 630 Oakwood Ave., Suite 221, W. Hartford, CT 06110, 203/249-8151.

For Preschoolers with Handicaps – Free Appropriate Public Education by 1991-92?

by Pascal Louis Trohanis

Congress enacted and on October 18, 1986, President Reagan signed Public Law 99-457 which amends the Education of the Handicapped Act (EHA). These amendments re-authorize a number of EHA programs and authorize a national policy and timetable for more and better services to young children with special needs and their families.

This new policy and schedule were generated because of several reasons: the needs of children and families; the documented benefits of early intervention; the existence of no mandate or entitlement for services to 3-5 year olds in over half of America's governing entities; and, the growing call for partnership roles among families, advocates, and professionals in planning and implementing services.

Two major programs of P.L. 99-457 serve as key catalysts to the improvement and expansion of services. The Part H state grant program for infants and toddlers with handicaps is discussed elsewhere in this issue of the FRC Report (see pages 14-15). The second, the Section 619 state grant program for preschoolers (ages 3-5 years) with handicaps, is described briefly in this article. Additionally, several challenges are raised in relation to the implementation of Section 619, including a call for building more partnerships with other preschool initiatives in states. The bottom line for the Section 619 program will be: Can it stimulate all of America's governing entities to offer and assure a free appropriate public education (FAPE) for every eligible preschooler by 1991-92?

Overview to Section 619

Section 619 P.L. 99-457 amended a previous portion of the EHA. This section creates enhanced incentives so that all states, territories, and the District of Columbia will provide a free appropriate public education to all eligible 3-5 year old children with handicaps by school year 1990-91 (or 1991-92, depending upon the availability of federal funding). Services may include instruction for parents and variations in child programming (e.g., home or classroom) and in duration (e.g., part or full day). And all other requirements of a state's Part B Plan for special education and related services (e.g., due process and procedural safeguards, evaluation and placement in the least restrictive environment, Individualized Education Program) must be instituted.

The incentives are created through the provision of special grants to states wishing to participate in this program. As of June 30, 1988, grants have been made by the U.S. Department of Education through its Office of Special Education Programs (OSEP) to all of America's state educational agencies (SEA). A minimum of 70-75 percent of these funds must then flow from the SEA to local educational agencies, intermediate educational units, and/or other contract agencies so as to develop and expand or improve community-based services. The remaining funds may be used by the SEA for statewide program development, cooperative planning with Part H, training, and administration.

Photo: Northwest Center Child Development Program

Congress allotted $180 million during the 1987-88 school year and $201 million for the 1988-89 school year for these special grants to help implement this national policy. State allocations are based on a complex formula. It is derived from the number of 3-5 year old children with handicaps currently receiving special education and related services (e.g., $300 per child for 1987-88 and $400 per child for 1988-89). Also, states may receive additional monies for an estimated number of youngsters who will receive services for the first time. These grant monies are to serve as incentives to help convince states to develop, expand, improve, and routinize programs and are not intended to pay for the entire cost of these preschool services.

If a governing body (state) does not establish a FAPE policy by 1991-92 (at the latest) for its 3-5 year olds, Section 619 contains some penalties. Failure to adopt this policy will result in a loss of these particular federal preschool grant monies, as well as the Part B State Plan formula grant monies for these youngsters. Also, the state may not receive selected EHA discretionary grants for such projects as research, demonstration, and training that address the needs of 3-5 year olds.

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Some Challenges

State and local service providers, advocates, and parents face a number of challenges as they actively get involved in Section 619 program development and implementation over the next few years:

1. How to insure that parents are accepted as partners in planning services for their children, especially in those governing entities where there is no history of an entitlement for universal specal education and related services to young children?
2. How to orchestrate the Section 619 grant activities with those of the state's Part H grant, especially in program areas such as child identification and screening, prevention, eligibility, transition, tracking systems, family involvement, and individual plans?
3. How to determine and characterize the child population to be served, especially along categorical labels or non-categorical dimensions?
4. How to conceptualize the least restrictive environment for preschool children with handicaps, especially when states do not have mandatory regular education or child development program settings for preschoolers?
5. How to assure that a sufficient number of qualified personnel will be available to operate these programs for preschoolers and families, especially in rural areas and those places with large culturally diverse and/or low income populations?
6. How to design or reform policies and get them accepted, as well as acquire the necessary state and local resources so as to implement predictable and sufficient services since the federal incentive grants are modest and not intended to pay for the entire costs of services?
7. How to design and install accountability mechanisms to insure program access, quality, and benefits?
8. Finally, how to establish effective partnerships between 619 programs and a host of other early childhood initiatives that are developing or are operative in states? These initiatives may include public and private child and day care, early childhood and parent education programs, state pre-K programs or pilot projects, and federal programs such as Head Start, Developmental Disabilities, Early Periodic Screening Diagnosis and Treatment (EPSDT) and the new Even Start program of Chapter I.

Closing

Section 619 of P.L. 99-457 can serve as a catalyst for new and improved opportunities for all of America's eligible youngsters, ages 3-5 years. To make FAPE a reality, and not just a dream, states must act thoughtfully in three ways: They must articulate a clear vision and philosophy for their desired service system for preschoolers with handicaps; they must make wise use of their special federal incentive grant funds; and they must make sound investments in their local communities by encouraging creativity, cash outlays, commitment, and collaboration among parents, advocates, and service providers.

Networking in New York State: A Green Thumb Experience

by Lisa Grippo-Gardner and Catharine McHugh

Outreaching and networking are no longer buzz words of the '80s. In New York State and throughout the country, we increasingly use these techniques to share knowledge and develop our awareness of appropriate and available services. Particularly in serving minority families, these efforts have played an integral part in the success of many agency's service delivery systems.

Two agencies—the NYS Commission on Quality of Care for the Mentally Disabled and the NYS Developmental Disabilities Planning Council—serving disabled populations in the New York State Capital district, wanted to improve outreach activities to minority communities. We recognized the importance of the cultural differences and socio-economic conditions of each separate minority group, and learned that nothing permeates family life more than ethnic identity. We also became aware of the significance of serving the whole family rather than attempting to provide one item on a laundry list of needed services, and, most importantly, discovered that information must be provided locally where minority families feel at home.

Through our individual outreach efforts and experiences, we were able to jointly form a network of agencies. It is our hope that others will benefit from the tips we have to offer about how our network began and blossomed.

Plowing the Soil

Families are clearly the essential resource in developing and maintaining quality care and services for the disabled. In recent years, families have created advocacy groups that are concerned about accessing services for their disabled family members and monitoring their quality. To help families accomplish this complex task, the NYS Commission has provided on-going advocacy training and technical assistance to more than 2,000 families.

During this period of outreach, the Commission became keenly aware that minority families, particularly those who are Spanish-speaking, were under-represented in the family group movement throughout the state. In the Capital District area, for example, there was a growing population of Hispanics, numbering close to 10,000, who lacked services because there were too few Spanish-speaking social service and health workers to deal with their needs. Clearly a minority network was needed in this upstate urban and rural region to let families know about a variety of services that were available to them and to their disabled family members.

A statewide training conference sponsored by the Commission brought a wide range of service providers, outreach workers, and advocates together to focus on better serving the needs of minority families. As a result of this conference, the way was paved to structure a minority network.

A Seed is Planted and Sprouts

We began with fewer than twenty names of individuals representing a broad brush of agencies and organizations, from a two-person United Tenants Office to the NYS Department of Health employing thousands of professionals. Our first meeting was an introduction and sharing of information about the services we provided. The diversity of the group was mind-boggling at first, but we soon discovered we served the same families and encountered many of the same difficulties. Despite our varying sizes, resources, and purposes, we felt like jigsaw pieces quickly fitting together to form a picture. We also identified others to invite to future meetings, hoping to complete the puzzle.

By our second meeting, the original group of seventeen had grown to forty-two representatives. Some of the additional members had been identified through specific outreach visits to agencies or by other participants, and brought special expertise that strengthened the group. For example, four Hispanic women from different organizations were looking for a broad-based support group to bring some of their ideas to fruition. They represented very different Spanish cultures and helped us in identifying specific outreach techniques that worked best for these Latino communities.

Also new to the group were persons familiar with the Black community in the Capital District area who had worked diligently in outreach efforts designed to strengthen Headstart programs and services to the elderly. They invited members of the network to join them in a grassroots task force to improve services to Blacks in their locality. We welcomed these new participants and, inspired by their ideas, were determined to develop some group-wide goals. The one single tie that bound us together was that all members were interested in providing direct information to minority communities about the services and programs available to them.

The idea of an information fair surfaced as a project that could include all of our diversity while providing help to minority communities as individual agencies. To enable people to get information locally, we decided on several fairs in different locations. Groups worked on the fairs in their own communities but shared information with all the network members.

In undertaking such a project as a network, we learned the following:

- Identify an activity that all network members can benefit from, but not all need to be directly involved in.
- Use existing and available materials, mailing lists, sites, technical expertise (i.e., printing and graphics designers or individuals' knowledge of different ethnic groups) to accomplish the activity, avoiding the need to come up with new resources.
- Plug into activities that are already scheduled, adding your focus to a special segment of the activity and leaving the overall planning and implementation work to the original coordinators.
- Report back to the network members on the strengths and weaknesses of the activity (especially if they were not directly involved) to give them the benefit of your experiences.

Watering the Garden

Building on successful experiences, the network was eager for a larger project and has undertaken work on a statewide minority training series designed to develop a better awareness of individual ethnic groups in New York State. Different formats and presentations will be offered at different sites, and each will include a wide range of family service providers, organizations, and agencies.

The minority network is thriving with a minimum of care because the need for its existence is very real, and the activities it undertakes are simple ones which grow out of its members' experiences and knowledge. Our network has continued to grow, encompassing New York City with the addition of 400 agencies, organizations and individuals. Networks are not artificially created or complex; they can expand the potential of agencies and individuals with existing resources and funding. Agencies, organizations, and groups in New York State are tending their gardens a little better now because of the network. We hope minority families will reap the harvest.

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Catharine McHugh, MA, Special Education, is Coordinator of Training, NYS Commission on Quality of Care for the Mentally Disabled.

Both Catharine and Lisa are members of the Family Resource Coalition.

Contacts: Lisa Gardner, Catholic Charities Developmental Disabilities Services, 98 Slingerland St., Albany, NY 12202; Catharine McHugh, New York State Commission on Quality of Care, 99 Washington Ave., Albany, NY 12210-2895, 518/473-7869.

▲Programs ▲Serving ▲Special ▲Needs ▲Families

Photo: The Rehabilitation Institute of Chicago

●Serving a very low-income population in the Bronx, the **Family Partnership Program** (FPP) responds to the special needs of families caring for children with significant developmental disabilities at home. The program helps families make use of existing resources, and/or enables them to overcome the limitations of inadequate or incomplete services.

Two major strategies are used to strengthen the caregiving capacities of families: a resource credit system and service advocacy. The emphasis throughout is on flexibility and partnership—the program makes resources available to families, and the families decide how best to use those resources.

Through resource credit, FPP makes support monies available to families at one of three levels of credit: $100, $200, or $300 per month, with assignment to a level based on individual assessment of the severity of the child's dysfunction, family income, family caregiving capacity, and availability of assistance from other sources.

Family guides assist families in developing a 6-12 month plan for the use of their resource credit funds. These may include in-home or out-of-home respite, transportation, special food and clothing, as well as home modifications and equipment. When asked to do so, guides can assist families in finding a supplier of goods and services or help to negotiate prices. The resource credit approach provides families with substantial discretion in selecting support services, and then helps arrange a form of payment with the family and the provider.

The advocacy and service coordination component of the project offers assistance to families in obtaining access to services for which they're eligible. Family guides provide information about existing programs and services and then help with applications for Medicaid-financed home care, identification of out-of-home respite programs, arrangements for educational programs, location of health and rehabilitation services, and assist with housing problems.

FPP has played a strong role in strengthening inadequate service coordination among Bronx agencies by promoting information sharing, convening meetings of service providers and families to enhance communication, and preparing a consumer guide to service resources through an interagency effort.

In its first year, FPP served 140 families. Financial aid was provided to 80 families, and 60 others received advocacy and coordination services. Core program staff are a director, two family guides, and an administrative assistant. The service program operates on an annual budget of $280,000 of which $138,000 is reserved for financial support.

Contact: Kathleen McKaig, Director, The Family Partnership Program, 1180 Rev. James A. Polite Ave., Bronx, NY 10459, 212/542-0030.

▶FRC *Member*

●**Parents Helping Parents** (PHP) is a free-standing, nonprofit resource center for families of children with birth defects, acquired disabilities through sports or vehicular accidents, chronic or terminal illnesses. A 12-year old volunteer group of parents, professionals, and lay counselors, PHP also services parents of learning disabled children, the nearly drowned, intensive care nursery high risk and preemie babies, and parents who have lost children through miscarriage, stillbirth, or neonatal death.

The organization offers families emotional support, information, peer counseling, direction, training in advocacy and communication skills, a stress outlet, time, and attention. Psychosocial support is provided to parents by parents experienced in raising a special child. Operating on the premise that there is no substitute for "someone who has been there," hundreds of trained parents whose children have a variety of handicapping conditions are matched with parents of children with similar disabilities through the Visiting Parent Program. PHP also operates a program for the siblings of all special needs children, and produces a newsletter and other publications for professionals and parent groups.

PHP believes that parents of special needs children must be well informed about their children's rights, understand how to advocate for them, be aware of available programs and services, know how to access the systems of support, avoid being socially isolated, and be knowledgeable about their child's abilities and strengths.

PHP is also committed to training professionals toward better ways of communicating and working with families of handicapped youngsters, and educating the public about the on-going emotional, social, and financial needs of these families.

Contact: Florene M. Poyadue, Director, Parents Helping Parents, 535 Race St., Suite 220, San Jose, CA 95126, 408/288-5010.

●**Parents Reaching Out** (PRO) was born six years ago out of the frustration of a group of parents in the Albuquerque area who had young children with developmental disabilities. Feeling unsupported, impotent, and discouraged with New Mexico's lack of services and systems, these parents determined that major changes in policy and attitude were needed and set about making them happen.

Pragmatically, PRO realized that if New Mexico was to serve its children with disabilities appropriately, families would have to be recognized as the ultimate caregivers and decision-makers for their children. It meant organizing diverse groups of parents all over the state, getting professional training in the health and education fields, learning about the funding priorities of agencies and institutions, and dealing with attitudes toward disabled children and their families and the role of parents in making policy.

PRO is active throughout the state with families who are ethnically and economically diverse, and often geographically isolated. They provide peer support, act as advocates, develop information services, educate the public and professionals about children with handicaps, secure services, and promote early diagnosis and identification. PRO has created major legislative changes for their population, sponsored conferences, and continually expanded their state activities and regional groups.

PRO parents have led the efforts to create a Medically Fragile Children's Program, lower the school age to three for children with handicaps, and developed a high-risk health insurance pool. Hundreds of families have received PRO's advocacy training in order to work with their legislators, school personnel, and those who write policy.

Through their Family Support Project, PRO provides help to parents who choose to keep a handicapped child at home. Training in case management and financial planning aids families directly; PRO also assists communities to develop respite care programs, helps form local parent support groups, and networks existing ones.

Contact: Sally Vancuren, Director, Parents Reaching Out, 1127 University NE, Albuquerque, NM 87102, 505/842-9045.

● Profound deafness, when it occurs before language and speech are acquired, is more than simply not being able to hear. It can be a barrier to communication, isolating a person from the surrounding world. Most deaf children are born to hearing parents who often see their parenting role with an overwhelming sense of inadequacy.

Providing supportive programs and services for these parents is an integral part of the **Lexington School for the Deaf** in New York City, a multi-faceted agency serving 425 hearing impaired children from birth to 21 and their families. Parent programs at Lexington sensitively address the stages of anger, grief, mourning, and denial that parents experience over their children's newly diagnosed deafness. School-related activities also help hearing parents learn about the deaf community which their child will likely join, a culture that has a language (American Sign), social clubs, newspapers, colleges, folklore, and customs that parallel those of ethnic minority groups.

Infant Center staff see babies up to age three, and primarily assist parents through diagnosis and adjustment, helping them gain information, skills, and emotional strength to nurture their hearing impaired infant. Activities include individual infant/parent sessions, group parent meetings on coping and language/communication, play groups, and family socials.

The preschool parent program fosters a "parent as parent, parent as teacher" model. Parents participate in monthly visitation day in their child's classroom, meetings on deafness and child development, family counseling, mothers' and fathers' counseling groups, and library and telecommunications loaner programs.

Learning to read, and then reading to learn, is important to all children, but especially for the elementary school-age deaf child. Most deaf children need a great deal of help from their parents with this challenge, and the school offers continual support and encouragement to parents.

The deaf adolescent from a hearing family must integrate as role models both his/her parents as well as deaf adults. Parents are acquainted with adult deaf role models, community and governmental agencies working with deaf adults, and are also helped to understand the implications of deafness on adolescent development.

Photo: Lexington School for the Deaf

Traditional parent programs have three major goals: participation, education, and training. Lexington has also developed parent programs which serve the wide spectrum of ethnic and culturally diverse families in the student body. The Hispanic Resource Team and the Black Deaf Children/Families Project focus on the bi-lingual, bi-cultural needs of students and their families.

Lexington School is a community of learners that includes the families of its students. An active, creative parent education program educates, enables, and empowers parents to accept their deaf children and to advocate for their optimal development.

Contact: Jean Steins, Parent Educator, or Oscar Cohen, Superintendent, at the Lexington School for the Deaf, 30th Avenue and 75th Street, Jackson Heights, NY 11370, 718/899-8800 or 3030 (TTY). ▶FRC

● The **Family Exchange Center** (FEC), located in a large neighborhood public school owned by Variety Pre-Schooler's Workshop (VPSW), offers a nontraditional approach of help to families of children 0-16 in special education classes or with special needs.

The Center provides respite, recreation, information, counseling, and mutual aid. Parents share responsibility with the professional staff, identifying their own needs and program preferences. Together they develop, provide, and monitor services. The FEC system of support is different from conventional professional offerings because it views parents as collaborators and members rather than as patients or clients.

Established in 1983, the FEC rationale emerged from experience with families in the VPSW, a special education program for very young children with learning, language, and behavior problems started in 1966. Although early intervention gave the children the education they needed, it did not address the plight of their parents whose well-being affected the outcome for their handicapped youngsters. With rare exception, developmentally disabled children are born into families who can not be expected to have the specialized knowledge, skills, or support systems to deal with their child's special needs, nor the community resources most other families take for granted. Despite stress and the difficulties involved in developing good parenting skills, most families do not seek professional counseling.

These observations prompted the organization of a new model of service. The FEC, with its combination of traditional counseling, programs to meet articulated parental needs, and mutual aid network, put a competence-enhancing community resource in place.

From a practical point of view, FEC is a place with year-round afterschool, afternoon, and Sunday programs which include recreational, spectator, and social activities for the entire family, each of its members, or children only. Parents select and fit their family needs into a menu of services and activities provided by the Center and its staff. Annual evaluations examine parental satisfaction, identifying changing needs, priorities, and preferences.

FEC builds programs based on the following assumptions: Parents are the most indispensable family program planners; like all families, those with disabled children differ greatly in their personal adjustment, functioning, and nurturing capabilities; periodic family dysfunction and parental confusion and anxiety can be normal reactions to child care burdens.

The FEC answers the commonly stated parental need for respite, information, comfort, and consolation. It creates an informal social network, and provides opportunities for family members to simply enjoy one another's company and to make new friends. An expanded dialogue between the staff and parents often prompts troubled but hesitant parents to seek appropriate professional services.

These respite programs give parents relief from child care. The children benefit from both mainstreamed programs shared with their siblings and the children of staff members. The community also benefits, from cost-effective prevention and families who balance self-reliance with community resources.

Contact: Judith Bloch, Executive Director, Variety Pre-Schooler's Workshop, 47 Humphrey Drive, Syosset, NY 11791, 516/921-7171. ▶FRC

Photo: Family Consortium Project

● In the past, large segregated institutions were the main form of residential care for Ohioans with developmentally disabling conditions. Eventually, a variety of community-based group and cluster-care programs emerged, but none of these options necessarily included the most fundamental part of the individual's lives—the involvement with their already established informal system of family members and friends.

Ohio's pilot **Family Consortium Program** (FCP), unique in the nation, is a family-developed, family-centered, and family-driven program model. It not only assumes family/friends' involvement is important—it is dependent upon them. The family/friends form a consortium which serves as the administrative body that manages certified homes in which people with developmentally disabling conditions reside. The residents, along with the consortium members, choose their new home and the people who will become their roommates. A maximum of three can live in a home; the amount of staff support is determined in the Consortium's budget which is based on their needs.

Consortium members—families as well as residents, when appropriate—are responsible for selecting and carrying out personnel functions and overseeing programming of the homes. The state funds supporting this project reimburse the consortium for the direct services of the staff. Other operating costs are absorbed by the consortium and could include buying/leasing/renting a home, purchasing insurance, food, furnishings, etc.

Current participants range from age 8 to 43 and involve a variety of capabilities. Three of the four homes in the pilot project house adult women; the fourth is a residence for children with multiple handicapping conditions.

This alternative is not meant to meet everyone's needs. It is particularly for families who have the desire to utilize a living situation for their son or daughter that maintains the family as an integral unit while allowing the individual to grow and gain needed autonomy and independence. In order to achieve this, families voluntarily put themselves in the sometimes difficult situation of administering a home, supervising employees, managing state funds, negotiating with other parents, and acting as on-call crisis intervention person.

There isn't anything mystical that drives the parents pioneering this project; however, as one said, "Only a parent who has been haunted by the uncertainty of a special child's future can know the joy of being a part of this program."

Contact: Vicki Grosh, the Ohio Department of Mental Retardation and Developmental Disabilities, 30 E. Broad St., #1201, Columbus, OH 43266-0415, 614/644-7747. ▶FRC

● Each year, 350,000 premature and critically ill newborns are cared for in Neonatal Intensive Care Units across the United States. As technical support of these infants progresses, routine hospital systems are often inadequate to meet the emotional needs of their parents. Thrust into dramatic medical situations, parents can be easily overwhelmed by shattered expectations, lack of information, and the financial impact of the baby's care. As a result, parent support groups have been formed across the country, growing from 12 in 1979 to 350 currently.

One of these groups is **Parent-to-Parent** (PtP) at Children's Hospital of Orange County which has served parents since 1979. From that time to the present, the goal has been to offer emotional support to new parents and to provide additional resources as needed. PtP has always enjoyed complete support from physicians, nurses, and social workers, and is a vital link in the hospital/medical team.

While health care providers who work with ill newborns and their families offer help and encouragement, no one understands the hardships as well as someone who has experienced them. Direct one-to-one support, therefore, is provided by fifty trained "graduate" parent volunteers who have survived similar life crises. Both in the hospital setting and at home after discharge, support can be continued for as long as needed through telephone and personal contact, with the aim being a healthy baby within a stable, intact family.

A group coordinator is available at the hospital two days per week to meet with staff and administer to the needs of parents. Parent meetings, a newsletter, and library services are also available. Funding is provided by grants and donations.

PtP is part of the local Infant-Parent Support Network of Orange County, and is also a member of the international Parent Care, Inc., organization.

Contact: Linda Scott, P.O. Box 5700, Orange, CA 92667, 714/997-3000, ext. 8521.

● Looking at the current family-centered **Project DAKOTA** (PD), it's important to understand that a complete transformation of service delivery philosophy and practice took place to bring the program to its present state.

PD was funded in 1983 as a demonstration model to provide direct early intervention services to children, birth to four, whose disabilities ranged from mild to severe. In their original school-type model, youngsters with similar disabilities were bussed to segregated, sheltered special education classrooms in large school buildings where staff provided center-based services. Families were required to deal with a constantly changing group of professionals, and staff was troubled by problems with bussing and their inability to break down service delivery to reach into community settings.

Re-examining their goals and mission, their values, resources, and team structure, PD developed a new transdisciplinary team that took a wholistic view of the child. Professionals blended their expertise so that active teaching and learning across disciplines occurred; parents took on a leadership role and became vital members of the team; assessment and planning became collective efforts; and implementation was carried out primarily by one staff person through active consultation with other disciplines.

Services are custom-tailored to the needs of an individual family. Natural settings and community resources are used in programming, including neighborhood playmates, nursery school and tot programs, day care, extended family, and other settings used by non-delayed peers. Three times a year, a team assessment determines the child's progress and what future focus will best enhance overall development. Each team, composed of a teacher, a speech clinician, an occupational therapist, and a half-time paraprofessional, provided services to 25-30 families on a consistent, long-term basis.

DAKOTA is currently moving into yet a further phase of development in turning over its services to local public school systems as they assume responsibility for serving children with special needs from birth. Several DAKOTA publications are available which may be helpful to early intervention programs.

Contact: Linda Kjerland, Director, Project DAKOTA Outreach, 680 O'Neill Dr., Eagan, MN 55121, 612/454-2732.

● The **Family, Infant and Preschool Program** (FIPP) offers home-, center-, and community-based support services to handicapped, disabled, and developmentally at-risk children and their families. Its primary mission is to provide services in ways that strengthen family functioning and enhance the family's ability to raise their child with disabilities at home.

A philosophy known as Proactive Empowerment through Partnerships (PEP)

guides FIPP's intervention, research, and training efforts. The PEP philosophy is put into practice in FIPP's intervention services and demonstration and outreach projects which include assessment, planning, and intervention.

Once a year the family meets with a transdisciplinary team of an educator, speech therapist, social worker, psychologist, nurse, staff pediatrician, and physical therapist for an assessment planning session. The family's case coordinator facilitates this session through pre-planning meetings with both the family and the team members, and an individualized family support plan is written as a follow-up. Although one day a year is devoted especially to assessment and planning, modifications are made throughout the year to reflect the family's changing needs, goals, and resources.

In addition to assessing the child's strengths and needs, three aspects of the family are also assessed: the family's needs and goals, its functioning style, and its social support and other resources.

Through clinical experience and research, FIPP has found that interventions are more effective when they address needs identified by the families rather than those identified by the professionals. Families often identify needs that are not directly related to the child (e.g., transportation, employment) but which, if they remain unmet, interfere with their ability to tend to certain child needs. There is a distinction between needs and concerns when assessing families. Concerns are conditions that lead to a recognition that the difference between what is and what ought to be is sufficiently disparate to warrant attention; needs are conditions that lead to a recognition of what resources are needed to reduce this disparity.

In many instances, families do not explicitly specify their needs but rather share their concerns (e.g., worries, interests, and aspirations). Families are helped to "translate" concerns into needs through an assessment of the family's functioning style (intrafamily resources), their social support network, and other extrafamily resources.

In assessing the family's style of functioning, FIPP identifies their strengths and capabilities and how they are used to mobilize resources to meet their needs. Often, families have difficulty stating their strengths, and staff assists in this process by listening and observing.

Photo: Northwest Center Child Development

FIPP also assesses the family's extrafamily resources with special emphasis on their social support network. This process generally starts with the family generating a list of sources of social support, moving from those sources closest to the family (e.g., relations, friends, neighbors, co-workers) onto more formal support systems (e.g., social organizations, professionals). A family-identified need or project is then used to explore how resources existing within the family or their social support network could be used to meet their need. Often this includes consideration of previously untapped resources. The process of assessment, planning, and intervention are interwoven and ongoing.

The goal of the intervention is to support families in ways that enable them to become more competent, independent, and self-sustaining in their abilities to mobilize their social network to get needs met and obtain desired goals. FIPP has found this is the best way to assure that child needs are met.

The process of empowering and strengthening families occurs in every interaction that the professional has with the family. It occurs by seeking and respecting the family's perception of the strengths and needs of the child and the rest of the family, by honoring the needs and goals identified by the family, and by building on the family's strengths and recognizing the family's decision-making role.

In addition to direct services to families, FIPP operates demonstration projects, provides training, and conducts an extensive research program. Feedback from these activities is used to modify and refine service delivery efforts.

Contact: Jean Gowen, Associate Director, Family, Infant and Preschool Program, Western Carolina Center, 300 Enola Rd., Morganton, NC 28655-4608, 704/433-2731. ▶FRC

"The professionals should use their talents and expertise to help the family survive and function, to renew its strength and foster its cohesion. For it will be the family that will provide the long-term help required by the disabled infant. The family's daily decisions, routines, and relationships will translate into the support, the therapy, the special education, the recreational efforts, and all the other aspects of the best possible quality of life for the disabled child."

C. Everett Koop, M.D., Sc.D.
Surgeon General of the United States

● Rarely a day passes without a news item about child care—its scarcity, quality, or affordability for the working family. However, rarely a day passes with any comment about employed parents whose needs for quality child care are compounded by the fact that their children have handicaps.

Though children with disabilities are being provided with child care through a variety of arrangements, one program in Seattle, Washington, serves as a model for child care in a typical early childhood environment.

Since 1980, **Northwest Center Child Development** (NCCD) Program has operated a mainstreamed early childhood program for approximately 125 children and their families. On a daily basis, 90 children, half of whom have handicaps ranging from mild to severe, and half of whom are typically developing, learn and play together. Ranging in age from four months to five years, the children are grouped in "family units" with infants and toddlers to three years being accommodated in smallest groupings, and children who are 3-5 years grouped in slightly larger units.

Comprehensive services at NCCD include special education, early childhood education, pediatric occupational/physical therapies, nutritional counseling, nursing services, family counseling, physician referral, and full day child care. Children with handicaps receive their special education and therapies in the natural environment of the classroom, delivered by the appropriate therapist and educator.

The NCCD philosophy is best described as providing a supportive relationship to parents and accepting their individual parenting styles. All staff members view their respective roles as strengthening the family unit and accommodating the child's unique needs for specialized services with the parent's need for child care. As a result of this program philosophy, staff and children are engaged in experiences that allow for the greatest potential growth of each child.

Though the program was developed with the assistance of a three-year federal grant from the Department of Education, Handicapped Children's Early Education Program, and was initially supported by the funds, the program now sustains itself through ten different funding sources, including parent tuition for child care and state funds for children with disabilities.

Recent legislation, designated P.L. 99-457, mandates states to provide coordinated services to children with special needs by 1990. The intent of the law includes provision of those services to children with special needs along with children who are typically developing.

If a program's success can be measured by its waiting list and community reputation, then Northwest Center has been successful in showing that mainstreaming and child care can play complementary roles and meet the demand for quality child care for all children.

Contact: Linda Gil, Program Director, Northwest Center Child Development Program, 2919 First Avenue West, Seattle, WA 98119, 206/286-2322. ▶FRC

Editor's Note: *There are outstanding resources of all kinds to assist families and professionals as they care for children with special needs. The following are just a few examples.*

National Organizations

The Council for Exceptional Children
1920 Association Drive, Reston, VA 22091-1589
703/620-3660

CEC is a membership organization for special education professionals who serve special needs children in almost 1,000 local chapters, student associations, federations, and special education divisions. Members benefit from periodicals, special ERIC and CEC information services, conferences, and conventions. Catalog of professional products and services available.

National Maternal and Child Health Resource Center
College of Law Building, University of Iowa, Iowa City, IA 52252, 319/335-9046

The Center promotes the expansion and improvement of maternal and child health services including services for children with special health care needs. Center activities include provision of technical assistance, development of training materials, and information dissemination. Their block grant also has seed money for Special Projects of Regional and National Significance (SPRANS grants) such as demonstration projects, training programs, genetic disease and hemophilia programs.

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue, White Plains, NY 10605, 914/428-7100

The March of Dimes' prevention focus is on the more than 3,000 conditions collectively termed birth defects and their causes — whether that be genetic, behavioral, or environmental. Through their volunteers and programs in more than 250 chapters nationwide, MD promotes healthy pregnancy and birth through research, medical services, and education. Catalog of Public Health Education Materials includes publications, educational kits, and audiovisuals for students, adults of childbearing age, and pregnant women. Instructive fact sheets available. Contact local March of Dimes chapter.

Association for the Care of Children's Health
3615 Wisconsin Ave., NW, Washington, DC 20016, 202/244-1801

ACCH is an international membership organization of health professionals and parents that promotes the well-being of children and their families in all health care settings. ACCH develops publications and media, and provides consultation services to help implement a family-centered approach to care. Informative publications: *Family-Centered Care for Children with Special Health Care Needs; Parent Resource Directory; Guidelines for Developing Community Networks;* the *ACCH Network Newsletter,* and a variety of parent-focused pamphlets. Audio visual materials include: *Seasons of Caring* and the newly issued *Family-Centered Care.*

Sibling Information Network
Connecticut's University Affiliated Program on Disabilities, 991 Main St., Suite 3A, East Hartford, CT 06108 , 203/282-7050

Clearinghouse of information, ideas, projects, literature, and research regarding siblings and other issues related to the needs of families of persons with disabilities. SIN is a membership organization whose major activity is a quarterly newsletter. Articles and information deal with sibling issues that are written by and directed to family members and the professionals who work with families. Their new publication, *Kaleidoscope,* is aimed specifically at family members and explores a variety of issues across the life span of families who have members with disabilities.

The National Information Center for Handicapped Children and Youth
Box 1492, Washington, DC 20013, 703/893-6061

NICHCY is a free information service that assists parents, educators, caregivers, etc., on a broad range of topics concerning needs of children and youth with handicaps. Specializing in areas of education, they also make referrals to organizations and resources available at local, state, or national level. Strong emphasis on parent groups, networks, and connections. NICHCY publishes educational fact sheets on specific disabilities, a newsletter, and articles on current research and practices. They also offer technical assistance to parent and professional groups, and recruitment materials that encourage career involvement in fields of special education.

The Center on Human Policy
Syracuse University, 724 Comstock Ave., Syracuse, NY 13244-4230, 315/423-3851

Through its Community Integration Project and Research and Training Center on Community Integration, CHP has developed a variety of reports (available at minimal cost) and resources focused on integrating people with severe disabilities into community life, and dealing with services and supports to children and families. Write for full list of publications.

Mental Health Law Project
EI Advocacy Program, 2021 L St., NW #800, Washington, DC 20036, 202/467-5730

A national public-interest organization promoting broader availability of comprehensive early intervention programs for infants and toddlers. MHLP has worked with parents and providers in one state to organize an advocacy coalition, and currently coordinates an advocacy network to get statewide, family-centered, interdisciplinary EI systems in place to benefit from Title I of P.L. 99-457 funding.

Federation for Children with Special Needs
312 Stuart St., Boston, MA 02116, 617/482-2915

A coalition of parent groups representing children with a variety of disabilities, the Federation operates and coordinates information, advocacy, and training entities. Their TAPP project funnels technical assistance to parent centers nationwide through four regional centers which, in turn, help parents to participate more effectively with professionals in meeting the education needs of their handicapped children. The Federation's CAPP project encourages parent involvement in the health care of their children, and promotes parent/health professional partnerships, a system of information access, and peer support. Publications list available; brochure regarding other activities.

The Association for Retarded Citizens
2501 Avenue J, Arlington, TX 76006
817/640-0204

A thirty-three year-old volunteer organization that works to improve the quality of life for all persons with mental retardation. The ARC goals are based on research, employment training, family support, prevention, advocacy, information and community services, and programs of public education on all aspects of mental retardation. Publication list available.

The National Information System for Health Related Services
University of South Carolina, 1244 Blossom St., Columbia, SC 29208, 803/777-4435 or 1-800-922-9234

NIS operates a computerized, toll-free information system on tertiary or specialized services available for children with developmental disabilities or chronic illnesses, and for infants with life-threatening conditions. Currently serving all 50 states, trained counselors work with each caller to provide appropriate local referrals for medical, educational, and health-related services, plus contacts for parent support groups and parent training centers. There are also key agency listings by state on vocational rehabilitation, adoption, disabled child protection, and hospitals with neo-natal, cancer, and cardiac specialties.

National Lekotek Center
2100 Ridge Ave., Evanston, IL 60204, 312/328-0001

Lekotek is a worldwide system of learning and resource centers for children who have handicaps or special needs and their families. Based on play techniques that affect a child's learning capacity, both conventional and specially adapted toys are used to meet the developmental level of the child, and become the tools for growth. Trained Lekotek leaders model and demonstrate new play strategies to parents and children in monthly meetings; appropriate toys are selected and loaned to the family for reinforcement at home. Lekotek's Compuplay Center serves children who have physical, mental, behavioral, sensory, or emotional disabilities. Special software and adaptive equipment enable these children to create, explore, make decisions, play, and communicate using computers. In-service training for professionals is also available. Helpful publications: *A Guide to Toys that Develop Skills,* and *Planning Books for Making Adapted Toys for Children, Especially Those with Handicaps.*

The Kids on the Block, Inc.
9385-C Gerwig Lane, Columbia, MD 21046, 1-800-368-KIDS or 301/290-9095

This educational company sells an innovative puppet program used to dispel myths and misconceptions children and adults have about disabilities, to further appreciation for people's differences, and to open communication and understanding about sensitive social issues such as teenage pregnancy prevention, drug abuse, peer pressure, AIDS, and divorce. K on the B was developed to help non-disabled children deal with handicapped children being mainstreamed into regular classrooms. A further application of the puppets and their more than 24 topics have been developed into scripted programs, used internationally by rehabilitation centers, hospitals, school districts, and community service groups.

Clearinghouse on the Handicapped
U.S. Dept. of Education, Office of Special Education and Rehabilitative Services, Room 3132, Switzer Building, Washington, DC 20202, 202/732-1244

Responds to information inquiries, especially in the areas of Federal funding for programs serving disabled people, Federal legislation affecting the handicapped community, and Federal programs for the disabled. Send for their publications list that includes a Pocket Guide to Federal Help for Individuals with Disabilities, and the OSERS newsletter. Also available from the Government Printing Office: Directory of National Information Sources on Handicapping Conditions and Related Services.

Parent Care, Inc.
101½ S. Union St., Alexandria, VA 22314 703/836-4678

An international, nonprofit volunteer organization composed of professionals and parents dedicated to improving the newborn intensive care experience for babies, families, and professional caregivers. PC serves as an educational forum through conferences and seminars, a quarterly newsletter, and as a computerized referral source for parents and health care professionals.

Publications & Audio Visuals

Enabling and Empowering Families: Principles and Guidelines for Practice by Carl Dunst, Carol Trivette, and Angela Deal, (Brookline Books, 1988, 219 pp., $22.95 hardcover)

Recent Federal legislation (P.L. 99-457) requires that early intervention programs use a family systems model. This book was specifically written for early intervention practitioners who are being asked to take on expanded roles in their work with handicapped and at-risk children and their families, but who have not had extensive training in family systems assessment and intervention procedures. A blend of theory and practice, the book proposes tested principles and operating guidelines to enable professionals to help families identify their needs, locate the formal and informal resources and supports to meet them, and develop decision-making and problem-solving abilities to access resources. The focus is on building the family's capabilities to cope more effectively on its own.

In Time and With Love: Caring for the Special Needs Baby by Marilyn Segal (Newmarket Press, 1988, 192 pp., $21.95, hardcover & $12.95 paperback)

This book was written for parents whose baby is handicapped, developmentally delayed, or constitutionally difficult. Material was drawn from the experience and expertise of 24 families with special needs babies who participated in an interview study at Nova University's Family Center. Helping parents understand and deal with their feelings, this guidebook also provides accurate parenting information and practical suggestions. Above all, it presents an honest picture of what it's like to live with a problem baby. The well-known author is a developmental psychologist specializing in early childhood who is also the parent of a handicapped child.

Respite Care: Principles, Programs and Policies by Shirley Cohen and Rachel D. Warren, (Pro-Ed, 1985, 228 pp., paperback)

The purpose of this book is to help families of the severely disabled by presenting the case for respite care, and to mobilize the people who can take action to expand the scope of such services. Written for professionals in developmental disabilities as well as newcomers to the field, and those who are interested in family support. Among many helpful overview and practical chapters, the appendix is essentially a step-by-step procedural guide for establishing respite care programs.

Parenting Your Premature Baby Series Valencia Community College, P.O. Box 3028, Orlando,FL 32802, 305/299-5000

A series of fifteen four-page newsletters aimed at reassuring parents about daily life with a high-risk child. Each issue contains articles on parenting, a medical problem common to preemies, a reading list, child development information, and a list of resources. Can be purchased as an individual series at $20, or in bulk orders. Write for complementary copy.

The Exceptional Parent, 605 Commonwealth Ave., Boston, MA 02215, 617/536-8961

Published eight times yearly, EP magazine is a practical guide and product information source for parents of disabled children. Feature articles, editorials, book reviews, and a family life section appear regularly. A recent issue included material on how supported employment works, why persons with disabilities can and should work at real jobs, ways in which professionals undervalue parents' knowledge, and toy ideas for younger children. Their book, *The Disabled Child and the Family: An Exceptional Parent Reader,* is a compilation of outstanding articles (softcover).

Coordinating Council for Handicapped Children 20 E. Jackson Blvd., #900, Chicago, IL 60604, 312/939-3513

A coalition of parent and professional organizations that informs and activates parents regarding the special education rights of their children with handicaps. Publications: *How to Organize an Effective Parent/Advocacy Group and Move Bureaucracies; How to Get Services by Being Assertive;* pamphlets and fact sheets on special education rights, tax benefits, and specialized services.

Young Adult Institute, 460 W. 34th St., New York, NY 10001, 212/563-7474

Children with Special Needs is a training system providing information and support for families and professionals. There are six half-hour tapes for each of the following topics: Parent Issues, Family Issues, Therapeutic Issues, Developmental Milestones, Transitional Issues, and Professional Issues. Guest interviews are used in a format that also includes personal vignettes. Accompanying guide provides additional activities and resources. ½" or ¾" tapes: $45 each/rental, $75 each/purchase and shipping. Brochure available.

On Becoming a Special Parent — A Mini Support Group in a Book by Marcia Routberg (Parent/Professional Publications, P.O. Box 59730, Chicago, IL 60645, 1986, 131 pp., $7 paperback)

The author developed this handbook of practical how-tos, hints, and advice based on her own needs as parent of a child with cerebral palsy. Her suggestions cover emotional issues, as well as guidance through the maze of special education and therapy, dealing with medical people and hospitals. The book includes a special needs glossary, and could be helpful to professionals in gaining insight to special needs families.

Ways (First Publications, Inc., P.O. Box 5072, Evanston, IL 60204)

A magazine published quarterly, Ways deals with issues of mental disability with a long-term focus on integrating special needs people into the community. Recent issues included articles on supported employment, accessing information sources, a guide to psychiatric medication, self-sufficiency trusts, a Q and A page, and book reviews. Both parents and professionals can benefit from broad-ranging variety of material.

Alternatives, A Family Guide to Legal and Financial Planning for the Disabled (First Publications, Inc., P.O. Box 5072, Evanston, IL 60204, 1983, 194 pp., $18.95 ppd. paperback)

Chapters on wills, guardianship, trusts, government benefits, taxes, and insurance comprehensively cover and explain complex legal and government requirements for families as they study the options and make plans for the future.

Message from FRC's President

by Bernice Weissbourd

There is much to learn from this issue of the FRC Report. In its pages we are privileged to share feelings poignantly expressed by parents of special needs children. We hear the discerning questions of professionals. We note the gaps that exist when the professionals' focus on the child limits his/her understanding of the parent. We think in broader dimensions about the power of unconditional love between parent and child. We are reinforced in our knowledge of the effect of community attitudes on families' lives. Throughout, we have a vague but pervasive feeling that perhaps we have never fully understood either the anguish or the strength of the mother and father and siblings who comprise the family of special needs children.

The stories of special needs families in this Report underscore what is common to all families—the child's need to be cared for, the parents' requirements for acceptance, information and social support, the vulnerability of families in the face of pain and disappointment, and the unknown and unexpected resources they can muster to deal with crisis. We are reminded of the barriers society puts in their path.

The Report leads us to think of the special values cherished by those in the family resource movement. We speak of them often. They include caring for others and recognizing our interdependence, a concern for the well-being of all families, and a commitment to ensuring all children get the kind of start that will maximize their potential from birth. We function on the premise that parents' self-esteem largely determines their ability to encourage a good sense of self in children. We believe that children cannot be seen as separate and distinct from the family, nor the family as separate and distinct from the community in which it lives. And we translate these beliefs to meet the needs of individual families in their particular culture.

As we read this Report, our particular role emerges in clear outline. It is to assure that families of children with disabilities have the opportunity to develop the relationships that all families need in order to thrive, relationships that provide both emotional and concrete support. It is to assure that communities and professionals care about special needs families, and build on their strengths. It is to use our talents and experience to assist families to provide the best possible quality of life for their children with disabilities. It is to act as advocates in a community to assure that special needs families do not feel isolated or rejected, but are an integral part of an environment that enhances their capacities to raise their children as they see fit.

I think this Family Resource Coalition Report is not only informative, it is inspiring. It vividly reveals that as we shape our responses to special needs families, we inevitably build better communities, and as we integrate special needs families into our programs we enrich the lives of all families.

Acknowledgement: This FRC Report is a significant departure in format and focus—it is four pages longer than usual and carries a single theme. We have been privileged to draw on the expertise of member/specialists in the field of special needs families, and want to thank Linda Gilkerson, Vicki Grosh, Elizabeth Jeppson, and Eleanor Szanton for their guidance and involvement.

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